Annual Report 2016

octapharma

Winner of 11 Communication Awards 2017

IT'S IN OUR BLOOD

Revenue

€1.6bn

+6%
2015: 1.51

Operating income

€383m

+9%
2015: 351

Employees

7,094

+14%
2015: 6,213

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Who we are

Octapharma is one of the largest human protein product manufacturers in the world, developing and producing human proteins from human plasma and human cell lines. As a family-owned company, Octapharma believes in investing to make a difference in people's lives and has been doing so since 1983; because it's in our blood.

Visit Octapharma's Annual Report website to experience our patient story videos:
www.annualreport.octapharma.com

Vision: Our passion drives us to provide new health solutions advancing human life.

Mission: For the safe and optimal use of human proteins.

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Advancing human lives.
It's in our blood.

Wolfgang Marguerre – Chairman & Chief Executive Officer

Revenue

€1.6bn

Employees

7,094

I am proud to introduce this special Annual Report that focuses on the patients whose lives are being transformed by our therapies. Profiling the stories of children, women and men in Argentina, Brazil, Canada, Europe and the US, this report reflects our company's vision: "Our passion drives us to provide new health solutions advancing human life." I have been moved by the passion and courage of all participants, including the families, patient advocates, nurses, physicians and scientists supporting patients with rare and complex diseases. Thanks to all interviewees for their openness in sharing their stories.

Since I founded Octapharma in 1983, the company has grown into a truly global group. At heart we remain a family business but we are now a much larger family, employing 7,094 people and serving patients in 113 countries. This year we achieved record-breaking revenue of €1.6 billion and pre-tax profits of €388 million.

We have been investing in the future to continue to grow in a sustainable way, including increasing our fractionation capacity to help even more people in need. Our five company values – Ownership, Integrity, Leadership, Sustainability and Entrepreneurship – will continue to guide all our decisions and actions.

Committed to meeting the increasing demand for Octapharma's plasma-derived therapies, we are expanding our fleet of plasma donation centres. A very important milestone was the US Food and Drug Administration (FDA) approval of our new state-of-the-art plasma testing laboratory in Charlotte, which will give us greater control and further strengthen our operations.

We are committed to developing novel solutions to address the unmet needs of patients with rare diseases. We are accelerating the development of new products in both our plasma and recombinant product pipelines. Our new third generation 10% intravenous immunoglobulin (IVIG), panzyga®, was launched in Canada, and is expected to reach other major markets in 2017 and beyond. We also submitted our new fibrinogen concentrate for registration in the EU, the US and Canada.

Many patients are making the switch to our fourth generation, human cell line derived recombinant factor VIII (FVIII) product, Nuwiq®. The development of inhibitors remains the biggest challenge for patients with haemophilia.

Our official interim results from the previously untreated patient (PUP) study, NuProtect, were presented at the World Federation of Hemophilia (WFH) World Congress in Orlando and vindicate our proof of concept.

Octapharma continues to invest heavily in clinical trials – both registration studies to support marketing authorisations for new products and studies to support new indications for existing products. Recognising the individuality of patients, we are continuing important clinical studies in "personalised prophylaxis" for haemophilia A and B patients with Nuwiq® (NuPreviq) and our factor IX (FIX) product octanine®F (ProNINE).

Access to medicine continues to be a persistent dilemma in many countries for a variety of reasons, from lack of diagnosis and knowledge to insufficient healthcare systems and conflicting priorities. Octapharma supported the WFH Humanitarian Aid Program with several million IUs of Nuwiq®.

In 2016 I celebrated both my 75th birthday and 33 years since I founded Octapharma. These anniversaries cause reflections on the progress we have made in terms of advancing science and treatment options. I want to thank all Octapharma staff for their commitment to the company and its well-being. My family is committed to leading this company into the future. We will continue with our efforts to provide patients worldwide with our lifesaving therapies.

Wolfgang Marguerre
Chairman & Chief Executive Officer

Investing in strong governance. It's in our blood.

From left to right, standing:

SIGURD KNAUB
RESEARCH AND DEVELOPMENT

FLEMMING NIELSEN
PRESIDENT, OCTAPHARMA USA, INC.

FREDERIC MARGUERRE
SHAREHOLDERS' REPRESENTATIVE
PRESIDENT, OCTAPHARMA PLASMA INC. USA

WOLFGANG MARGUERRE
CHAIRMAN & CHIEF EXECUTIVE OF THE OCTAPHARMA GROUP

TOBIAS MARGUERRE
MANAGING DIRECTOR, OCTAPHARMA NORDIC AB

ROGER MÄCHLER
CHIEF FINANCIAL OFFICER

From left to right, seated:

MATT RIORDAN
BOARD MEMBER

JOSEF WEINBERGER
CORPORATE QUALITY AND COMPLIANCE OFFICER

NORBERT MÜLLER
BOARD MEMBER

GEROLD REMPETERS
CORPORATE PRODUCTION OFFICER

OLAF WALTER
BOARD MEMBER

Our Board of Directors' decisions are guided by our five company values. **Ownership** means that we take responsibility and are fully accountable for our conduct. Our **integrity** guides us to live by high ethical standards and care less about being right than about doing the right thing.

The cornerstones of great **leadership** are always leading by example and striving to be the best at what we do. **Sustainability** reminds all of us to focus on the long term and of meeting the needs of patients not only for today but also for tomorrow. Our **entrepreneurship** honours our roots while encouraging innovative thinking to inspire progress.

Focused on patient care.

Transforming patients' lives since 1983, Octapharma is dedicated to empowering more patients to go further in their life adventure.

HAEMATOLOGY

In people with bleeding disorders, the clotting process doesn't work properly. In haemophilia A, haemophilia B and Von Willebrand disease (VWD) factor VIII, factor IX or Von Willebrand factor (VWF) respectively are missing or don't work as they should.

This causes these patients to bleed for a longer time than those whose blood factor levels are normal. Most bleeding occurs internally, into the joints or muscles. Repeated bleeding without prompt treatment can damage the cartilage and the bone in a joint, leading to chronic arthritis and disability. Early on-demand or prophylactic therapy that replaces the missing coagulation factor is able to effectively control or prevent acute bleeding in this group of patients.

READ ERIC'S STORY 17

IMMUNOTHERAPY

People with immune deficiencies are prone to severe infections due to a lack of naturally occurring protective antibodies (immunoglobulins). These patients need replacement of the missing immunoglobulins in order to protect them against infections and ensure they can lead a normal life.

Conditions where the immune system is out of balance are generally referred to as immune-mediated diseases, of which auto-immune diseases are a well-known subgroup. Immunotherapy treats immune diseases and deficiencies by inducing, enhancing, or suppressing an immune response through immunomodulation or immunoglobulin replacement therapy.

READ GABRIELA'S STORY 37

CRITICAL CARE

Patients in intensive care and emergency care often require immediate medical attention to prevent shock and quickly restore the body's natural balance – such as normal blood volume and clotting (coagulation) function.

Plasma and plasma derived products are used by emergency medicine physicians and paramedics around the world in life threatening and severe medical situations.

READ LISA'S STORY 49

WATCH TADEO'S VIDEO
annualreport.octapharma.com/patients

I WANT TO BE A SUPERHERO.

ALEJANDRO AND SOFIA
PARENTS OF TADEO, 6
SALTA, ARGENTINA

Our lives are marked by two major "before and after" moments. The first was when our oldest child Mateo, who is 13, was diagnosed with severe haemophilia A. The second was when our son Tadeo, who is six, was diagnosed with insulin dependent type 1 diabetes at two years old.

Tadeo's diagnosis with severe haemophilia A when he was two months old was not a surprise because of his older brother's condition. When Tadeo was born, our main fear was of the consequences of him being born prematurely and not of him having haemophilia like his brother. When he was diagnosed we were already prepared to face his haemophilia and we knew we were accompanied by the team at the Haemophilia Foundation of Salta.

From the moment Tadeo was diagnosed with type 1 diabetes, his haemophilia became second priority for us. Today, haemophilia is not limiting Tadeo's daily development in any way because his factor VIII concentrate, Nuwiq®, is performing well. Tadeo's treatment twice a week gives us peace of mind and reassurance that at least his factor VIII levels are stable. Mateo is also doing well on octanate®. He acts as Tadeo's protector by cherishing and protecting him against harm.

It is important to explain our children's haemophilia to others because there is so much misunderstanding and even misinformation in society. One of the major challenges we face is the ignorance of teachers at school. We counteract this by giving people clear and accurate information. We explain that Tadeo is not being harmed, his condition is not contagious, and we tell them where to call in an emergency situation.

"From the moment Tadeo was diagnosed with type 1 diabetes, his haemophilia became second priority for us. Today, haemophilia is not limiting Tadeo's daily development in any way."

The Foundation has had a significantly positive impact on our lives and on our kids' lives. Through it they have met other children with haemophilia. The Foundation has given us counselling, training and support, and without it we would not know what to do as parents. Whenever we have questions the Foundation welcomes us with open arms. Our kids feel empowered and protected with their continuous prophylactic treatment.

Tadeo's diabetes is one hundred times more powerful than haemophilia because it is more difficult to control. Our biggest challenge is to maintain stable glucose levels in his blood. Diabetes gives us no rest throughout the day because it is directly related to food intake, exercise, climate and the mood of the child.

Tadeo takes 16 units of insulin in the morning, and then at least eight on-demand doses of insulin as we monitor his blood glucose levels throughout the day. Tadeo manages his symptoms and knows when he has high or low blood sugar. He does not handle his medication or dosage; for that he depends on an adult with knowledge of his pathology.

Our advice to a family who has discovered that their child has haemophilia is: get support and educate yourself. Do not overprotect your child. Do not listen to advice from doctors who do not know this pathology. Do not go to healers who can supposedly cure haemophilia with natural preparations. Teach your child the importance of prophylaxis and how it is performed. Give your child tranquillity and a sense of security.

As parents we are free thinkers. We are committed to learn each day and to grow together with our children. We can make mistakes and we can try to learn from them. We instil joy, positivity and responsibility in our children. We share the most we can with them. Our goal is always to promote independence.

Tadeo never gets bored. He loves to play with other children and enjoys swimming and physical education at school. He loves superheroes and playing video games. Tadeo collects action figures of Dragon Ball, a Japanese manga series.

Tadeo's dream is to be a superhero.

A DIAGNOSIS OF HAEMOPHILIA IS NOT THE END OF THE WORLD.

DR MARIA SOL CRUZ,
PRESIDENT OF THE HAEMOPHILIA FOUNDATION OF SALTA

The Haemophilia Foundation of Salta is dedicated to the diagnosis and comprehensive care of people with haemophilia. In the Salta province we have 63 people with haemophilia (45% of whom are children), 100 with Von Willebrand disease and 20 affected by other factor deficiencies. We offer diagnosis, treatment, multidisciplinary care and information about the diseases and how to improve quality of life.

In Argentina local healthcare professionals often do not have the knowledge or training to treat haemophilia. There has been insufficient understanding of how to take care of people with bleeding disorders, and often there were misunderstandings and mental barriers. The Foundation acknowledges and faces these challenges by developing educational programmes for healthcare professionals, as well as programmes educating patients and families.

The most important job we have is to demystify haemophilia. Prophylaxis means that children today do not have the same orthopaedic problems and joint problems experienced by adults who did not have prophylaxis growing up. Today families do not have to be afraid of this disease. A diagnosis of haemophilia is not the end of the world.

Our main role is to support families by providing tools, know-how and advice. Empowerment comes when the family understands the disease. Our families have direct connections with the Foundation, and access to a network of multidisciplinary physicians and healthcare professionals.

An early diagnosis is as important as getting the right treatment. In Latin America we are often lacking the tools and specialised laboratory staff to support diagnosis. The first challenge is proper diagnosis, and then providing proper treatment on time. One of our goals is to help physicians better understand the condition and the importance of treatment. Another goal is to inform and educate society, for example to expel the myth that children with haemophilia are prohibited from playing sports. To support families we have created guides for parents and teachers, and we go to the schools ourselves to educate them.

It has been a challenge to demonstrate the value of our work. Early attempts to establish a healthcare unit dedicated to haemophilia were initially rejected by the Ministry of Health. I was very glad when an Act was signed by the Ministry of Health in July 2016 formally acknowledging the importance of the Foundation's work.

After going to the World Federation of Hemophilia (WFH) World Congress in Melbourne Australia, in 2014, we made a legal request to use Nuwiq® before regulatory approval in Argentina. Authorisation was granted and currently we have four patients on compassionate prophylactic use of Nuwiq®. My experience of this product has been excellent. With the pre-filled syringe, it's easy to prepare, it's quick to infuse and the half-life is great meaning fewer infusions a week.

Tadeo's case is special because he has two diseases: severe haemophilia A and type 1 diabetes. It is unfortunate, but it gives us the opportunity to try to better understand the impact of having these two major diseases at the same time. We are learning every day how to improve things for him. I am very glad that Tadeo's parents are so engaged in understanding what they can to improve his quality of life.

I love working with families and having social interactions with many different people. I love taking care of people and seeing them improve each day. I travel internationally and nationally and am constantly learning. I am always eager to come home and apply and share the knowledge I have gained.

Mother Teresa said: "Not all of us can do great things. But we can do small things with great love." What we do may appear to be small, but when done with love it can have a huge impact.

WATCH NATHAN'S VIDEO
annualreport.octapharma.com/patients

HAEMOPHILIA IS JUST A PART OF WHO MY SONS ARE, LIKE BEING TALL.

DARRYL, FATHER OF NATHAN, 7
NEWMARKET, ONTARIO, CANADA

My sons Nathan (aged seven) and Ben (aged nine) have lots of energy and are very funny and entertaining. They play basketball and want to play in the NBA when they grow up. I coach their basketball teams, and before they go to practice I infuse them with their factor concentrates. Nathan and Ben have severe haemophilia A. Ben loves all sports, and most of all he would love to play hockey; even today he still asks why he can't play. For my boys, hockey and American football are out of the question.

Strange bruises started appearing on Ben's body when he was 10 months old. He had really bad swelling and luckily our paediatrician was on the ball and recognised the symptoms of bleeding and referred us to the SickKids Hospital in Toronto. The diagnosis tore us apart. It was shocking. We were confronted with understanding what this condition would mean for our son, and figuring out how we were going to live with it. Our life trajectory changed in a huge way. We didn't deal with it well. We went through a grieving process, mourning what we thought our life was going to be. There was a lot of fear.

Eventually we came to realise that the diagnosis wasn't life *ending*, but it was life *changing*. Having the support of our healthcare system and working with nurses taught us a tremendous amount. We learned that if we give the treatments right our kids are going to be fine. Now we have found a very good path to live with the diagnosis. In fact, all the family have been very active in the bleeding disorder community, including grandparents, on the national board and at local level. We talk to newly diagnosed families and give them tools to help them face the diagnosis.

"God, grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference."

The kids get their factor concentrate every other day. We have been doing home treatment for seven years. You get into the routine. We have to get up early to do it. Infusing my sons every other day helps me to do my job as a father, and them to do their job, which is to be kids. We make the most of the time we spend doing the infusions. We talk; in fact we are getting really good at talking, and not all families take the time to do that.

Ben was 20 months old when he bit his tongue badly. The recombinant factor we gave him triggered an inhibitor. We had only been living with this condition for 10 months and suddenly the treatment no longer worked. It was a double blow. We quickly learned how to administer immune tolerance induction (ITI), which pushes the body into submission. Imagine infusing 3,000 IU of factor every day in a two year old; Ben's current dosage is half that. Ben was inhibitor free within a year, but it was a hard year. No kid wants to have to sit still for an hour. We used to lay him down and wrap him in a towel to hold him still. Even now we battle with trust issues because we had to do things that in the mind of a kid were traumatic. He just didn't understand, and I think that had an impact.

The haemophilia treatment centre (HTC) team worried that Nathan would develop an inhibitor like his brother. They recommended he use wilate®. First it was used on demand whenever he got a bleed, then at nine months old he started prophylactic treatment with wilate®. Thankfully the approach worked and Nathan did not develop an inhibitor.

It's hard when you are a little different but my sons' haemophilia does not define them; it's just a part of who they are, like being tall. This year our boys went to haemophilia summer camp for the first time. It's great for their confidence to go away for a week and be with other kids with haemophilia. It gives them a feeling of independence. Nursing staff are there to give factor if the kids don't know how. Ben is learning to self-infuse; he puts his hand on his nurse's hand, and is becoming more active. They should be in charge of how they live with their condition. Learning to self-infuse means they can decide when and if they infuse, and they are in charge of the consequences. We want them to own it.

Every time my cell phone rings I always check, even if I'm in a meeting, because it might be the school and my first thought is: "Oh my god, what's happened?"

Haemophilia has made them more compassionate and caring kids. We go to the SickKids Hospital twice a year and spend a lot of time in the same clinic as children fighting cancer. Being exposed to kids and young people with life-altering challenges has an impact. When compared with those kids, our boys just have to get a needle every other day. It allows them to be more supportive and empathetic. I am amazed by their poise when I give them their injections, and their perspective on life.

We are very fortunate with the healthcare system we have in Canada. We've got it good; but it could always be better and our goal should be to make it better. There have been great advances in treatment, and pharma companies continue to do research into how to make these conditions even easier to live with. As leaders in the community, we need to make sure we safeguard our fantastic healthcare system and ensure that we don't take it for granted. We also need to advance awareness globally to ensure that children in other countries are given access to treatment for this very treatable condition. It ought to be a human right not to live in fear of injury because of haemophilia.

I am not religious, but my mantra is the serenity prayer: "God, grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference."

EVEN WHEN I'M IN PAIN, I FOCUS ON ALL THE POSITIVE THINGS.

ERIC, 18
UNIVERSITY STUDENT, STUDYING HISTORY, WINNIPEG, CANADA

I am grateful for everything I have in life. Living with severe haemophilia A has made me humble and has taught me a lot about how to cope with challenges. I don't think there is a lot of value in feeling down about yourself. Yes, the diagnosis sucks, but at some point you realise: this is my life, and feeling sad doesn't help me or anybody else. You always have something to be grateful for. Even when I am in pain, I focus on all the positive things; for example, at least I can still move my arms.

Even though things can get really bad, it does get better. For me, I have suffered a lot with chronic nerve pain and my inhibitor. I don't want to cheapen living with haemophilia, but haemophilia with an inhibitor is almost a completely different condition. An inhibitor is brutal. When I was 16 months old, I developed an inhibitor which means that my immune system identified my factor product as being non-self and developed antibodies to fight it. My body eliminated the factor immediately, so clots wouldn't form. As a small child I was put on immune tolerance induction (ITI). It's a tough regimen which involves daily treatment with large volumes. The treatment didn't work so I went on factor VIIa prophylactic treatment and also used it on demand.

In eighth grade I had what I thought were a series of bleeds in my knee, back and hip. I had a month and a half of bed rest where I could only lie on my side which was very frustrating. Eventually, after an MRI scan, they discovered there had been no bleeding and there was no physical damage. My body was simulating pain and inflammation. I was diagnosed with chronic nerve pain. We had been chasing phantom bleeds – I had gone through all that pain for nothing. I felt disillusioned. This had been draining on me, the family's resources and on the healthcare system. I eventually came out of that difficult situation through a combination of the correct medication and physiotherapy.

When I was 14 my haematologist suggested we give ITI another try. I was a teenager at this point, so the decision was mine to take. I committed to an 18-month trial and was tolerised in only three months; I was 15 years old and that was a huge turning point for me. I moved to treatment every other day with 10,000 units of wilate®. Now I can live my life the way I want to within my own limits. wilate® is how I control my quality of life by protecting me from bleeds.

Haemophilia has taught me how to deal with disappointment. Growing up, I got used to planned family holidays having to be cancelled because I got a bleed. It's disappointing for all the family, and although it's my fault I can't allow myself to feel super bad about it.

I've been talking about how complicated my life has been, but there are so many people around the world who do not have access to the treatment they need. Attending the 2016 World Federation of Hemophilia (WFH) World Congress in Orlando was a really humbling experience which blew me away. The major theme is "Treatment for All". Haemophilia is a manageable condition when you have access to factor concentrates, but 75% of people don't have access. For me, when I feel I am experiencing the beginning of a bleed, it is not a question of "if" I treat but "when"; I always have my factor available. Many people around the world don't have that luxury.

Haemophilia has shaped my interests and friends in many ways. As a kid I couldn't play sports. I played video games and board games. Having haemophilia means a lot of my interests are non-physical. I partake in what I call "mental athletics". In November 2016 I competed in the world championships of Netrunner, which is a two player card game set in a dystopian future. When I am playing competitive card games at the highest level I still feel the pain and the stiffness in my joints, but when I am truly involved in a game everything else falls away and I can just let go.

CHRISTINE, ERIC'S MOTHER

Haemophilia is in our personal lives and is now my occupation as well. I am Executive Director of the Canadian Hemophilia Society's Manitoba chapter.

At 14 months Eric bit his tongue; it was a tiny little cut but the bleeding didn't stop for days. We took him into the hospital and he was diagnosed with severe haemophilia A. Eric's diagnosis was like an out of body experience. We were processing things three seconds after they were happening. It is devastating to discover that your perfect child has a chronic condition. You experience anger and denial. You think of all the things that won't be; I remember my husband Shane saying: "He'll never be a police officer."

Once you have been through the grief process, you realise that this little person has all these other fantastic things to offer. You learn to become good managers of the condition – it becomes your normal. There was no way I would have put Eric into day care. I sold my business so I could stay at home with him. I was lucky to be in a position to do that. He is so cute, so it's worth it.

My advice to newly diagnosed parents is to learn all you need to know, but not from the internet which is full of scary things. Whatever you dreamed up in your head about the reality of this condition, it might not be the reality. Educate yourself and reach out to the community. During that dark time after diagnosis we very quickly made a strong community connection. During our first community event we saw kids running around being normal children. It was a huge relief to see that these were not disabled children, and to meet other parents who had been through what we were going through.

"I am so proud to see Eric's positive approach to life. When he was little and expressed anger we would talk about all the good things that have come from his condition – all the life experience we have and the people we know. You have to remember to see all the silver linings."

As a small child Eric developed an inhibitor and was put on immune tolerance induction (ITI). We did treatments every day through a port-a-cath. We did that for a very long time, but we couldn't get his titre level to change. We discontinued ITI then began using another plasma product that we gave prophylactically every other day two or three times a week – and used a bypassing agent when he was bleeding.

When Eric had his inhibitor he experienced profound bleeding episodes. When he expressed that he had pain there was instant panic. The experience of living with the inhibitor was a significant part of his young life. Since he tolerised at 15 years old, I have watched him gradually let go of his anxiety. Now he can experience the body pain everyone experiences. Yes, he pays attention, but there is not that same level of fear and anxiety, and that's the case for me too. When we got the news that he had tolerised I felt a weight lift off me that I wasn't even aware I was carrying. The difference between life with the inhibitor and life free from the inhibitor is incredible.

After everything we've been through we have learned an important lesson: every challenge is temporary. During the tough times it may not seem temporary, but you have to persevere and dig into your internal resources. You do the best you can, knowing that it won't always be like this. Having the chronic nerve pain diagnosed was a huge improvement in Eric's life because he finally knew why he was in pain all the time. Pain is so little understood, and is often undermanaged in bleeding disorders.

Our nurses have become a part of our family. The care from the team has been amazing. These people have known Eric all his life. Our haematologist, who is Director of the Manitoba Bleeding Disorders Program, was a Fellow when Eric was diagnosed. I have experienced the healthcare professionals working in the haemophilia realm to be truly dedicated to the people they serve, not only in terms of the care they provide but also their advocacy. We have been very lucky.

Eric has a resiliency and maturity not typical of his age. As a child Eric was socialised to adults early on; he was much more mature than his peers. Some older gentlemen in the community, who had experienced bleeding in their childhood and could remember what it was like not to have product, showed Eric kindness because of what he was going through. They became friends. The social skills he built up being around adults all of the time have served him very well.

Eric was 16 when he joined the gaming community, which is a beautiful community of people who have welcomed him and boosted his self-confidence.

I am so proud to see Eric's positive approach to life. When he was little and expressed anger we would talk about all the good things that have come from his condition – all the life experience we have and the people we know. You have to remember to see all the silver linings.


KNIGHTS
FOOTBALL

WATCH EDGAR'S VIDEO
annualreport.octapharma.com/patients

I NEVER LET HAEMOPHILIA DICTATE HOW I LIVE MY LIFE.

EDGAR, 31
JACKSONVILLE, FLORIDA, USA

The day I received my diagnosis of moderate haemophilia A at 10 years old was the worst day of my life. I was shocked and scared. My parents asked the same question every newly diagnosed family asks: "Is my child going to die?" It was like being in a tunnel and you looked ahead and saw no end. I felt like my life was being taken away from me. It was devastating. I grew up playing baseball and now I was told I couldn't play the sport I loved. At first it was hard to understand why. The hardest thing about haemophilia is knowing that there is no cure and for the rest of your life there are some things you can never do.

They say it takes a village to raise a child, and this is even truer when the child has haemophilia. After diagnosis I was referred to our haemophilia treatment centre (HTC) and to the Hemophilia Foundation of Greater Florida. Through education and networking events we met other families and gained a better understanding of the education materials and resources available. It sounds like a cliché but your haemophilia care team becomes like another family. When I was a paediatric patient my parents did most of the talking and they made the decisions; but as I grew older I had to learn how to communicate with the healthcare team and tell them how my treatment was working, for example if I thought I needed to increase my prophylaxis. I would advise the family of a newly diagnosed child to immediately surround yourselves with as much support as you can take in. Knowledge is power. The more you know, the better equipped you are and the better your quality of life will be.

"My parents asked the same question every newly diagnosed family asks: *Is my child going to die?*"

A great experience for me growing up was attending the weeklong summer camps for children with haemophilia at Camp Boggy Creek. I first went to camp when I was 11 and that's where I met a lot of my friends. In addition, one weekend a year there is a family retreat which is a great way for families to share experiences. It really helps to understand that you are not the only one. I went to camp every year until I was 16, and when I was 18 I volunteered for a few years to give something back and help young people see that having haemophilia is not the worst thing in the world.

Until you learn how to infuse factor VIII concentrate yourself you are always tied to a family member, HTC or nurse. You are always counting on them to take care of you. At first I didn't want to self-infuse because it's scary to stick a needle in your arm. However, I was trained by a nurse and began to self-infuse at 16. Once you learn to self-infuse you break away from the ball and chain of depending on others and your quality of life goes up. At the first indication of breakthrough bleeding or injury, you are able to infuse quickly, and in an emergency you don't have to wait. Self-infusion is a liberation.

When I was younger I was quite shy and kept myself to myself. Growing up and learning how to communicate and explain my haemophilia to adults means that today I am an open book. I use my life experiences to help other families. As Patient Educator for Octapharma, my role is not only to share my story but to listen to our community and guide them to resources that can help them. I am honoured to share my experience and the knowledge bank I have accumulated over the years – for example, teaching people how to educate employers, teachers and friends about

haemophilia. We have helped a lot of people understand that there is a solution to every problem that comes up.

I attended the 2016 World Federation of Hemophilia (WFH) World Congress in Orlando, which was truly eye opening. I met many patients from around the world and, despite differences in terms of availability of treatment, we shared many commonalities, such as physiotherapy techniques to use when you have a bleed. It was fascinating to find out that many countries are struggling to get medicine to patients or are not giving treatment to patients because of costs or availability of product. We are very blessed in the US.

My life has been enhanced because I know I am fully covered with my prophylactic treatment with Nuwiq®. I don't have to worry if I can do an activity because I know my factor levels are okay, and if something does happen I have the tools to take care of it. With my previous factor product I was having very uncomfortable adverse reactions, including dizziness, headaches and flushing. I switched to another product but went on to have 6–10 breakthrough bleeds a year, which is not the standard when it comes to prophylactic treatment. I happened to go to a Haemophilia A Consumer Roundtable meeting in Dallas, Texas and was amazed by the clinical data presented. From that day on I knew I wanted to switch to Nuwiq®. I did my research and started treatment initially on a free trial. I have been on the product since February 2016. I have not had any adverse reactions and zero breakthrough bleeds. I am ecstatic about my choice.

I stick to my infusion schedule very strictly, which comes from experience. Your teenage years are the most challenging time. You might not follow the prophylactic regimen properly because dealing with haemophilia is the last thing you want – you want to go to the movies or hang out with your friends. I am disciplined today because I know that my factor VIII product protects me. My daughter Amelia is one year old; since she was born I make sure I am taking care of myself because I want to be there throughout her life.

My life is very busy because as well as my job as a sales representative, and my role as Patient Educator, I coach high school American football five days a week. When you do what you love it's never work. I enjoy guiding young men and seeing them progress over the four years they are with me. Football teaches them valuable life lessons on how to stay calm and deal with difficult situations. It's great to see these young men evolve into valuable members of society.

I love knowing that I am making a difference in everything I do. I never let haemophilia dictate how I live my life. If I want to do something I always find a way to do it. With education and the correct support system I believe there is nothing you cannot accomplish.

WE HAD A CHILD WITH TYPE 3 VWD WHO DIED AFTER A HEAD TRAUMA.

DR FAISAL KHANANI, CONSULTANT PAEDIATRIC HAEMATOLOGIST ONCOLOGIST, TAWAM HOSPITAL, ABU DHABI, UNITED ARAB EMIRATES (UAE)

Our centre provides comprehensive care to 225 bleeding disorder patients. We try to treat all patients who come to our hospital; however, we are unable to treat patients who do not have insurance. Haemophilia can lead to disability if not treated, so it is very difficult when we cannot support all the families who come to us.

As well as 100 patients with haemophilia, our centre treats six patients with the rarest form of Von Willebrand disease (VWD), type 3. This most severe form of VWD is characterised by a total or near-total absence of Von Willebrand factor (VWF) in the plasma and cellular compartments, leading to a profound deficiency of plasmatic factor VIII (FVIII). We use wilate® for the treatment of VWD and haemophilia A, and as second line treatment for inhibitors with immune tolerance induction (ITI). In wilate®, ratios of VWF to FVIII are close to physiological values (1:1), facilitating ease of dosing and monitoring.

If bleeding is left untreated, this can be serious. We recently had the case of an undiagnosed type 3 VWD child who died after a head trauma. I hope that in future the introduction of genetic testing will lead to early diagnosis and treatment.

Working in haematology and oncology, it is very satisfying when you see a child cured or feel better and begin to enjoy life. It is wonderful to see the children do well at school. Some of our patients develop a fascination with medicine. One of my patients is in medical school and another is studying pharmacy.

I believe that life is a gift of God. We have to make the world more beautiful by living positively, not only for ourselves but for the community.

THE TAINTED BLOOD SCANDAL WAS HUGELY TRAGIC BUT VERY INSTRUCTIVE.

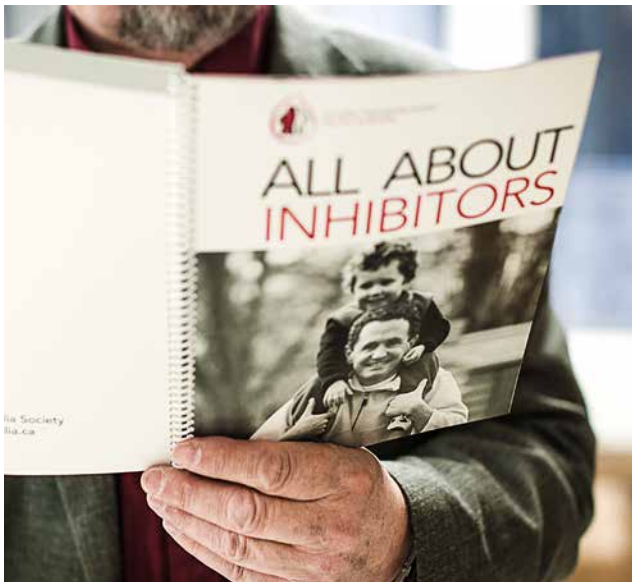
DAVID PAGE, 64
NATIONAL EXECUTIVE DIRECTOR,
CANADIAN HEMOPHILIA SOCIETY

I was born in 1952 and diagnosed with severe haemophilia B aged 11 months. My mother's uncles in England had died of haemophilia when they were young. In Montreal in 1953, a small group of haemophiliacs, their families (including my parents and grandparents) and physicians founded the Canadian Hemophilia Society.

In the 1950s and 1960s treatment for haemophilia B was fresh frozen plasma (FFP) administered intravenously which meant spending on average three to five days in hospital once a month. Each bag of FFP contained only small amounts of the missing clotting factor, so large volumes were needed to stop joint bleeding. FFP was not effective in serious surgery – a simple appendectomy, for example, was likely to be fatal.

It's a funny disease because one week out of a month you are incapacitated while the rest of the time you are almost normal. I missed a third of my school days, but it meant I had time to read. In the hospital I learned how to learn by myself, which is a tremendous life skill. In those days, kids were regularly staying in the hospital together and naturally you made friends. Today, because of home treatment children will only go into hospital once or twice a year for check-ups, so they don't foster those hospital friendships with other children with the same condition. These days, we manufacture those valuable connections through summer camps.

"My goal now is to pass on my knowledge to the younger generation. My message to young people is be knowledgeable and engaged in your own healthcare. This is your life."



In the early 1970s factor concentrates that could be infused at home became available. I learned quickly how to self- infuse and this changed everything. In 1972 I toured Europe by bicycle from England to Athens, which would never have been possible had I not had my concentrates with me.

Today we have kids who, because of the advances in treatment, are unable to identify bleeding when it occurs and don't know the consequences of bleeding. We need to educate these children about the causes of bleeding, how to identify bleeds and how to prevent them. Preventative treatment for children really makes a difference in the long run to the health of their joints. We want to raise kids so their joints are in good shape and they don't have to be repaired in later life.

Older people with haemophilia suffer with every step, because literally every step hurts. The damage was done in their youth. In addition to the pain, there is emotional suffering. Some feel socially isolated and unable to play a full role in society. Some might not be educated because they could not go to school. Some feel like a burden on their families. Young kids in Canada today will avoid almost all that pain and suffering. Yes, there are still frequent needles, but compared with the past, it is almost like night and day. Saying that, inhibitors are a parent's worst nightmare because when a child develops an inhibitor it's like travelling back in time 50 years.

By the early 1980s, the Canadian Hemophilia Society helped to build a network of haemophilia treatment centres (HTCs) across Canada to provide comprehensive medical care throughout the lifetime of patients. There are 25 HTCs in Canada. The patient is at the centre of a circle of care which includes a trained haematologist, a nurse coordinator, a physiotherapist for prevention and rehabilitation, a social worker, and a psychologist to support learning to live with a chronic disease.

The challenge for parents is finding the balance of not being over-protective, but equally not being under-protective and denying the disease. Some parents say: "My child is normal, he can do anything." That isn't quite true. I encourage people to learn about their child's condition and to be as open as possible with other people in terms of disclosure.

This has become a very treatable disease in the developed world, with life expectancy close to normal. In many countries, however, it is just like it was 50 years ago, with no access to factor VIII (FVIII) and factor IX (FIX) products, and lack of haemophilia expertise in the hospitals. Globally, 75% of people with haemophilia have inadequate or no access to treatment. Many people die before they reach 20, and if they do survive they are crippled. For the last 20 years the Canadian Hemophilia Society has run 10 successful twinning partnerships with developing countries to help them build their haemophilia organisations and support them to educate their members and advocate for care.

The infection of thousands of Canadians with HIV and hepatitis C was Canada's worst preventable public health disaster. It was a terrible time for everybody: individuals, families and healthcare providers. There are people still living with the consequences and some have been unable to rebuild trust in the healthcare system. The crisis was hugely tragic but very instructive. The Krever Commission (1993–1997) was set up to investigate allegations that the system of government, private and non-governmental organisations responsible for supplying blood and blood products to the healthcare system had allowed contaminated blood to be used.

Many of our members testified, including me. It was extremely hard to hear what had happened, and to learn that some of it could have been avoided. The Krever Commission led to many changes in blood systems worldwide and I am proud of what we achieved.

In Canada at the moment paid plasma donation is a hot issue. Our organisation takes the view that products from paid donors are as safe as those from unpaid donors. We need more plasma and the only way to get more plasma is through paid donors. This is heresy for some people because of the problems in the 1970s and 1980s. However people need to challenge their own preconceptions and look at the science and the facts. Things have really changed since the tainted blood scandal, and with all the scientific advances, lessons have been learned. The key issue is having a safe supply of product for patients.

We are a militant and demanding community. In general people with haemophilia tend to be obstinate. Once we get an idea we don't give it up easily, which comes from facing challenges as children and often dealing with medical people who didn't know what they were talking about. We knew which veins to use when we were four, and we were put in the hands of interns, so even as young children we had to assert ourselves to get the care we needed.

Fortunately, the younger people today don't have to go through what we went through in the 1980s. The Canadian Hemophilia Society is involved in lots of blood safety committees and medical conferences. We try to get the younger generation involved and allow them to take their proper place in decision making. My goal now is to pass on my knowledge to the younger generation. My message to young people is be knowledgeable and engaged in your own healthcare. This is your life.

WATCH JANNIK'S VIDEO
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A HYPERACTIVE KID WITH HAEMOPHILIA IS A DANGEROUS COCKTAIL.

JANNIK, 21
UNIVERSITY STUDENT, STUDYING JOURNALISM, MEMBER OF THE NATIONAL YOUTH COUNCIL OF THE GERMAN HAEMOPHILIA SOCIETY

I was a very hyperactive child and that is hazardous when you also have haemophilia. I have attention deficit hyperactivity disorder (ADHD). When I was young I would constantly run through the house and jump around. I was always up to something. With hindsight I can admit that I was quite annoying. I had so much energy and was extremely active, which resulted in a lot of bleeds. Bringing up a boy like me was quite intense for my parents and it was especially difficult for my mother. To have a hyperactive kid with haemophilia is a dangerous cocktail.

As a kid I found it very hard to accept my haemophilia. I used to wish that I didn't have bleeds and didn't have to go to hospital so often. Sometimes I would stay in hospital overnight. It was tough, but occasionally I enjoyed the hospital stays because it meant I could watch videos.

The most challenging time for me and my mother was from 9–11 years old. I found it very difficult when I had to learn to inject myself with FVIII product. It is tough for a young lad to infuse himself. It was very hard for my mother to manage everything that was happening and to cope with having a little kid that doesn't want to look after himself.

"I would rather see more factor concentrate treatment available for people throughout the world than a pill which was only available in Europe."

I remember being alone in my room and crying. I felt so frustrated. I couldn't play football with my friends. I always wanted to play but it was just too dangerous, especially since my ankle was a target joint for bleeds. All my sports teachers knew about my condition, and that meant that I couldn't take part in some sports lessons. I was angry that I wasn't allowed to be normal.

I grew up believing I had moderate haemophilia, but recently my doctor told me that I have severe haemophilia. It seems that I don't have as much factor VIII activity as I used to. My older brother has mild haemophilia and he is just like a normal guy. Today he is doing his dream job – he is a train driver. I am happy for him. He didn't have the problems I had growing up. He was never under prophylactic treatment. He was also a much calmer child. I was the big challenge for my mother.

My grandfather had haemophilia and he was a great man. I know that he didn't have the chance to get the therapy he needed. If he was alive today he would be very happy to see the medicine that is available and all the advances that have been made. I think as young people we should appreciate all that we have today. Sometimes we don't appreciate it enough; I know I don't. I have experienced a lot of challenges, but I was never in a situation where I had a bleed and no access to therapy. Unfortunately I take my medicine for granted.

I should take my prophylactic factor product twice a week, but sometimes I don't have the time to do it or I just don't feel like doing it. Taking this medicine feels like a burden. It's a stupid attitude, I know. I understand that it is important to take it in order to stay protected, but when you are young you don't always look after yourself as you should.

Today I lead a nearly normal life, although I have target joint bleeds in my ankle. My foot swells from the inside and turns blue, and if it is really severe I can't walk. I am very involved with the German Haemophilia Society. I am a Youth Representative on the Youth Council of Germany. This work is very enjoyable and it has emotional worth for me. Spending such a long time in the community forms a deep and heartfelt connection. My involvement started at its summer camp, which I attended almost every year from age nine until my 18th birthday. You get to know a lot of kids with haemophilia and you realise that you are not alone. As I got older I became more involved in the running of the camp and was given more responsibilities. The summer camps were amazing; in fact, these were some of the best times of my life.

I attended the World Federation of Hemophilia (WFH) World Congresses in Orlando and Paris – these events offer a great experience. You get the opportunity to meet people from all over the world. I would love to see the majority of haemophilia patients having access to products. Today, only 25% of people have access. If I had the choice in the future I would rather see more factor concentrate treatment available for people throughout the world, than a pill which was only available in Europe.

I am a musician and have played guitar since I was 11 years old. Reading and writing fiction are also great passions of mine. I recently went hiking in the mountains with a friend whom I met at summer camp. The fact that two young guys with haemophilia can go hiking really shows what modern treatment can allow. I would say to a young guy with haemophilia that he should participate in the community because we need him. I would tell him that he shouldn't take his treatment for granted. Live the life you want, because the medication today gives you that freedom.

SUSANNE, JANNIK'S MOTHER

When my sons were born I knew there was a chance they would have haemophilia; it is normal for us. Haemophilia has been in our family since the 1700s. My father had haemophilia and grew up during a time when no treatment was available and the disease was little understood. The doctors thought that vitamin C and eating lots of peanuts would help. Children were told they could not do sports and after injuries often they had to lay in bed for weeks. My father wanted to be a chef, but was told he couldn't because he would have to handle sharp knives. My father learned not to trust doctors. He believed that you were more likely to die in hospital than if you treated yourself at home. Even dentists were too scared to give him treatment. His brother lost a leg when he was young after cutting himself – they couldn't stop the bleeding. The first time my father was infused with a factor concentrate, in 1980, he contracted hepatitis C. I had convinced him to go to hospital for treatment to stop his nose bleeding. I felt guilty for a long time after that.

The connection between sons and mothers is usually very close and most mothers feel guilty about being a carrier of this disease. Even when you know you cannot change it and it was not your choice, in your heart you feel differently.

I was expecting my younger son Jannik to have mild haemophilia like my older son, but when he was born an inexperienced doctor said: "Don't let him cry, he will get bleeding in his brain." I was shocked. Despite knowing this was incorrect, he made me feel very insecure. I replied that it cannot be true because everyone in the family has always had mild haemophilia. Jannik was always considered to have moderate haemophilia. Only recently he has been shown to have severe haemophilia after all.

I didn't expect Jannik to have so many bleeds throughout his childhood. You could never predict what would happen next because of his hyperactivity. Being at home was sometimes like being in intensive care. It became too much for me – I had a lot on my shoulders. I felt destroyed. My husband could not help me that much, he could not see blood and he stood back. When Jannik was 10 years old I went with my two sons into rehabilitation for four weeks. I felt exhausted and during that time I asked the doctors to perform the injections. In the following year I realised it was finally time for Jannik to do his injections himself. But he said: "You do it or nobody will do it." When he was 11 years old, with the support of the home care service, Jannik learned how to infuse himself. What a relief!

In 2009 we built up a network for haemophilia families throughout Germany. The network consists of families with haemophilia who offer a helping hand or an open ear to other families. For three years I was a member of the Board for the German Haemophilia Society. I learned a lot during this time. In November I stepped down from the Board and now I am fully focussing my efforts on the network.

I am a Senior Home Care Specialist. We support patients and families with children with haemophilia with their therapies, and train them on home care treatment. Now we are seeing many refugees with haemophilia entering Germany. Some of these people have never had access to treatment before; some have subsequently developed inhibitors after treatment. It is very difficult for these people and there are some language barriers. We try to find a way through the chaos to support them.

We shouldn't grant this disease too much power over our lives. One can live a happy life despite having haemophilia. If one can accept help from others, many things become easier. I am really curious about the developments in the future and I hope that this disease can soon be treated even better.


GRUPO DE CAPOEIRA

WATCH ED CARLOS' VIDEO
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WHEN I AM DANCING I FEEL FREE.

ED CARLOS, 42
DANCE TEACHER,
DIADEMA, SÃO PAULO STATE, BRAZIL

I look healthy, so it might be hard for some people to believe that I have a disorder that impairs my immune system. It means I have a propensity to contract diseases more easily.

My first pneumonia crisis was when I was six years old, and throughout my childhood I was frequently hospitalised with pneumonia. When I was 13 years old my condition worsened. The air sacs of my lung had become inflamed and filled up with fluid, which is known as "water on the lungs". I had to have this fluid removed, and this happened many times over the next five years. Eventually when I was 18 years old I had to have one of my lungs removed.

When I was a child my mother and the doctor recommended that I start to do something to increase my lung oxidation. I started to play "capoeira", which is a Brazilian martial art that combines fighting, acrobatics, music and dance. I loved it, but after my lung was extracted I had to stop. I needed to look for another sport, and that's when I learned to street dance.

At 34 years old I had the worst pneumonia crisis in my life. I couldn't breathe – that's the worst sensation you can have. It was nerve racking – I thought I was going to die.

"If I met a plasma donor I would thank them and ask them if they know how much their act of giving is transforming people's lives such as mine."

Through this difficult time my greatest objective was to stay alive, and to get through this time and go on to complete a dance performance. Through these challenging years, my greatest supports have been my pulmonologist, the São Paulo Hospital, my mother and my wife.

My pulmonologist referred me to a specialist at São Paulo Hospital and at 35 years old I was eventually diagnosed with common variable immunodeficiency (CVID). The doctor told me there was no cure and I would have to live with this my entire life. I was scared, but also happy to have the answer after living with the condition for so long.

"Now the medication allows me to do everything that I want. I feel that I have been granted another life."

My family were also relieved to hear the diagnosis – they had been very worried about me and were tired. My condition had impacted on my family throughout my life. My mother, and later my wife, couldn't work because they had to take me to hospital or take care of me at home. They lost their days with me at hospital.

Of course it is difficult to live with the knowledge that there is no cure for my disease. But when I was diagnosed I was reassured to know that finally I would have treatment. Since I started on intravenous immunoglobulin treatment seven years ago I have not been admitted into hospital again. Now the medication allows me to do everything that I want. I started capoeira again, but I know my limits. I feel that I have been granted another life.

I have immunotherapy with octagam® 5% every month. With immunotherapy I live better and I can live like a true human. I see myself as having two lives: life before and life after immunoglobulin treatment. My advice to someone newly diagnosed with CVID would be: don't worry, immunotherapy will make you feel better because immunoglobulin is life.

My greatest passion is dancing because it really boosts my life. When I am dancing I feel a mixture of emotions: happiness, anxiety, expectation. Adrenalin courses through my body. When I am dancing all of my body moves, and now I am 42 years old each year brings a different challenge. My body doesn't respond in the same way it used to when I was younger. Street dancing needs physical strength. To maintain my physical condition I exercise regularly. I love to dance because I can meet my friends and can do a job that I like. My CVID introduced me to dancing – perhaps without this condition I would not be a street dance teacher today. What I enjoy most about street dancing is learning the choreography and then teaching it to my students. When I am dancing I forget everything. I feel free.

If I met a plasma donor I would thank them and ask them if they know how much their act of giving is transforming people's lives such as mine.

With immunotherapy, I feel like I am living another life.

WATCH GABRIELA'S VIDEO
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MY ILLNESS HAS GIVEN ME THE WILL TO LIVE.

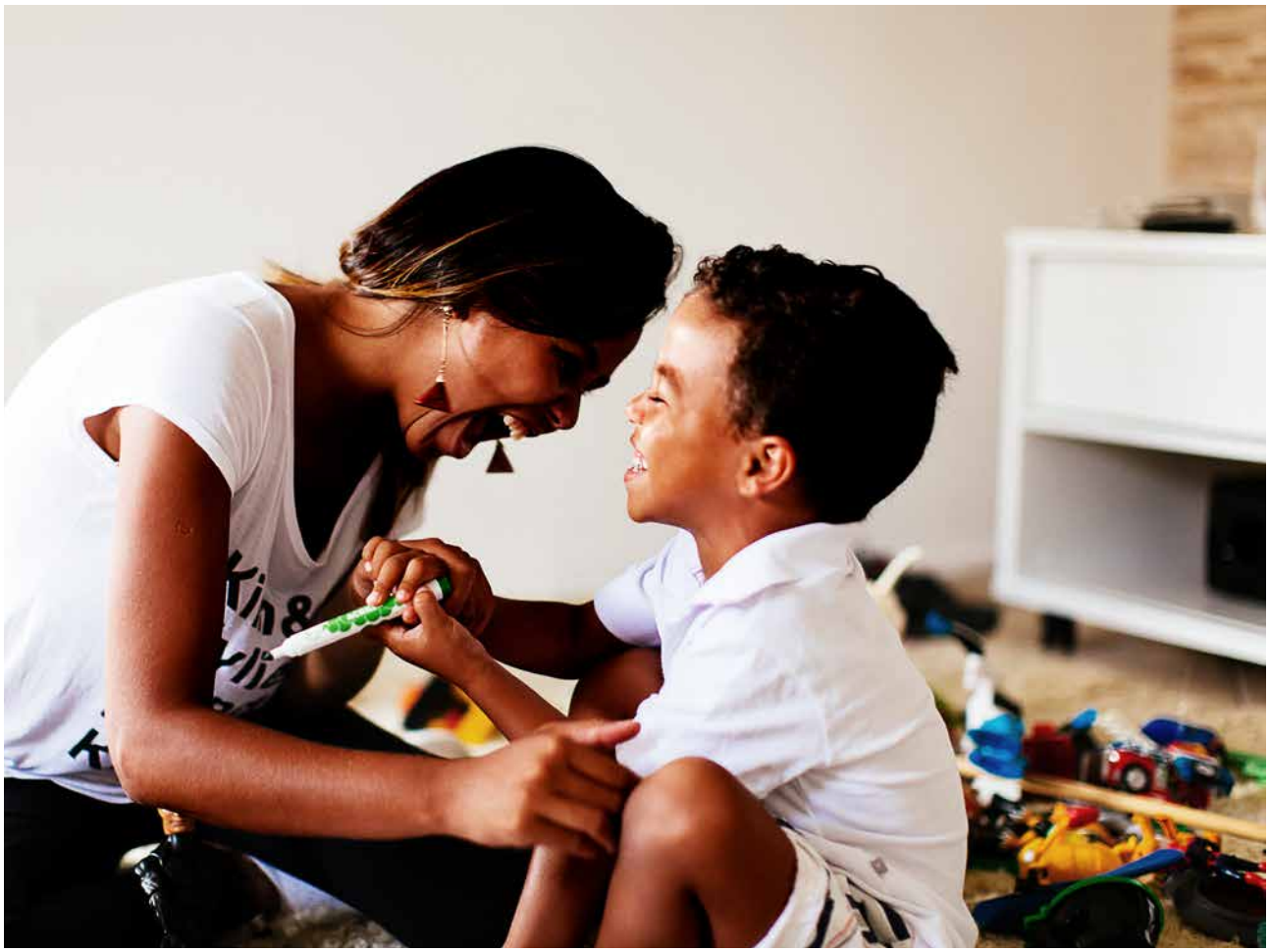
GABRIELA, 25
POLICE CLERK, SÃO CAETANO DO SUL, SÃO PAULO STATE, BRAZIL

As a child the hospital became my home. I had recurrent infections and hospitalisations, beginning at five years old. I lived one week in my house and one week at the hospital. My mother had to teach me lessons there so I would not fall behind at school. I could not play with other kids. I lost my childhood.

My worst memories of growing up were of the pain. I had terrible difficulties breathing. It was difficult for my parents to work and take care of me and my two sisters. I found it hard to watch as my family suffered for me.

When I was 12 years old I had two recurrent infections with hospitalisation. The last one was severe. I had upper gastrointestinal tract bleeding. I felt very bad. I was referred to an immunologist and she diagnosed me with common variable immune deficiency (CVID). I was happy to get my diagnosis because I was so tired of going to the hospital and no one knowing what was wrong. With the diagnosis I felt hope. After that initial relief I asked many questions to try to understand why I had this condition. Why am I the only one with it in my entire family? Why me?

"I lived one week in my house and one week at the hospital. I could not play with other kids. I lost my childhood."

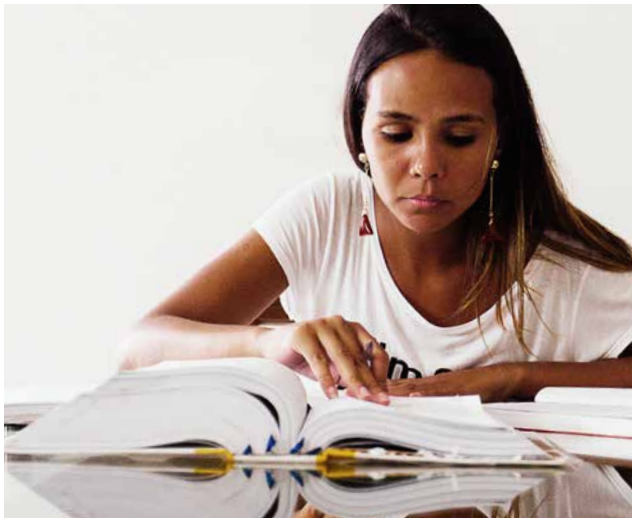


"If my health had been better growing up perhaps I would not have graduated in Law in 2015 and be a qualified lawyer today. My ambition is to be a chief of police."

My family, although they were scared and had many doubts, were relieved that finally their daughter would get treatment. It was hard to find out that there was no cure for my condition. Today my biggest concern is my four year old son. It is a possibility that he too will develop this disease. The thought of this happening to my little boy frightens me.

My relationship with my immunology team is excellent – they are very attentive, helpful, and professional. I have monthly intravenous immunoglobulin treatment with octagam® 5%. Since starting treatment I don't have recurrent infections any more. Before, I was just surviving, but now I am truly living. Today I live with no restrictions. My life has improved 100%. If I could change anything about my treatment, I would choose to do it at home.

My advice to someone newly diagnosed with CVID is: embrace this opportunity. In the beginning you may have many doubts but the immunoglobulin treatment will give you a new life and the possibility to live as you deserve. Now I can live a normal life just like anyone else. The treatment allows me to do everything. I can study, work, have a social life and dance samba. I can live!



If I met a plasma donor I would hug them and say thank you.

My illness has given me the will to live. It showed me how important my family is to me. My greatest passion in life is my son. Perhaps without this condition I wouldn't have the same values and attitude. I might not have worked so hard to finish my studies. If my health had been better growing up, perhaps I would not have graduated in Law in 2015 and be a qualified lawyer today. My ambition is to be a chief of police.

I believe that in life everything is possible. Nothing is impossible in the eyes of God.

PATIENTS USUALLY NEED LIFELONG INTERVENTION WITH IMMUNE THERAPIES TO LIVE HEALTHIER LIVES.

DR MATTHEW BUCKLAND, CONSULTANT IMMUNOLOGIST, ROYAL FREE AND GREAT ORMOND STREET HOSPITALS, LONDON, UK

The immune system's essential functions are to protect against infection, protect against cancer and prevent autoimmune disease. Primary immunodeficiency (PI) diseases are rare chronic disorders in which a part of the immune system is missing or doesn't function properly. Patients usually need lifelong intervention with immune therapies to live healthier lives. By supporting the immune system, infections are reduced and patients are better protected against progressive tissue damage. Some people used to go into virtual hibernation to avoid infection, but with treatments such as immunoglobulin replacement they are more protected.

It is important to understand what the patient wants to achieve with therapy. It is easy to believe you are doing a good job as a doctor if you have managed to get immunoglobulin levels up, but that may not be what is most worrying the patient. If you understand what their life looks like, then you can see how to best approach treatment.

Despite immunoglobulin replacement, some patients continue to get frequent or recurring infections. They can develop gut-related problems or inflammatory lung disease, which requires immunosuppression. The challenge is to prevent inflammation and at the same time the re-emergence of viruses or other pathogens. It can be a difficult path to tread.

My greatest hope is that we will be able to diagnose these conditions in early life before permanent damage is done. We have made great advances in understanding the genes involved in regulating the immune system. Newborn screening would allow us to identify and treat a condition before a child develops complications. In future we hope the affected gene could be edited, preventing morbidity and mortality in later life.

Immunology is genuinely fascinating and touches all areas of medicine. You to get to know people and their families over many years, which is very rewarding.

WATCH DONNA'S VIDEO
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IT'S AS IF A BIG HAMMER FALLS DOWN ON YOU. IT PUTS EVERYTHING INTO PERSPECTIVE.

DONNA HARTLEN, 46
EXECUTIVE DIRECTOR OF THE GBS/CIDP FOUNDATION OF CANADA

I started experiencing extreme back pain while on vacation in Halifax, Nova Scotia during Christmas 2009. I got into the bathtub every two hours to try to relieve the pain. I had a sore throat and I couldn't swallow properly. I was feeling weak. Days passed and things got worse. Then I got on the ground to change my two year old daughter's diaper and I just couldn't get up again.

This happened during the swine flu pandemic, so when I arrived at the emergency room I was put into isolation. They thought I might have swine flu. I had tingles in my tongue and I was very lucky the emergency room doctor recognised that my symptoms were neurological. The neurologist told me that I had either Guillain-Barré Syndrome (GBS) or multiple sclerosis (MS).

By this point I was losing feeling in different parts of my body. I was unable to walk or write my name. I had facial paralysis. I couldn't smile. I couldn't blink properly. I started losing my swallowing reflex. I am claustrophobic and have a fear of not being able to breathe properly. I was afraid I would lose the use of my lungs, which I knew was a possibility. I kept thinking the whole time: "Don't lose your lungs."

Four hours after being seen, I was put on intravenous immunoglobulin (IVIG). The immunotherapy slowed everything down. I was wheelchair bound but thankfully, because of the quick diagnosis and early IVIG treatment, I was not put on respiratory support.

"I was losing feeling in different parts of my body. I was unable to walk or write my name. I had facial paralysis. I couldn't smile."

When I was diagnosed with GBS I had no idea of the gravity of what that meant. I didn't realise it was going to take months away from my life. I ended up spending three months in hospital and three months in outpatient physiotherapy.

After an almost full recovery I was considering returning to work as an IT consultant. I had been off treatment for 15 months and was doing well. Then I had two relapses in early 2011 triggered by the flu. We were in Mexico on vacation. I had been feeling exhausted. I was having trouble getting up the stairs. I called the then Executive Director of the GBP/ CIDP Foundation, Susan Keast, who advised me to call my neurologist.

"I was fully paralysed, unable to move from the neck down. Being paralysed and aware of everything that is to come is scary. IVIG saved me and for this I am grateful."

I was diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP) after having another acute onset. CIDP is considered to be the chronic counterpart of the acute disease GBS. My symptoms are acute so I present like GBS, but because I am relapsing I am considered chronic. I was put on IVIG therapy and stayed on treatment until 2015. My treatments were eventually spread out to every six weeks. I became tired of the inconvenience of going to an infusion clinic and I wanted to try home therapy. I entered a study investigating subcutaneous immunoglobulin treatment for CIDP. This involved stopping IVIG treatment to see if I developed increased weakness. After three months of no IVIG treatment and no onset of increased weakness, I was released from the trial and deemed not to require treatment. Wonderful, or so I thought.

If I could live in a bubble things would be better. I picked up a virus – it was a typical cold. I developed sensory loss just up to my knees, and was walking like a duck. In March 2016, after being exposed to another flu virus, I had an acute onset of CIDP. I was fully paralysed, unable to move from the neck down. Being paralysed and aware of everything that is to come is scary. Throughout this I never stopped working my fingers and wiggling the toes which still had slight movement. I received IVIG treatment and a moderate dose of prednisone, and 10 days later I walked out of hospital using two canes.

The GBS/CIDP Foundation of Canada was there for me and my family when we needed them. I wanted to give back by supporting newly diagnosed patients. In 2013, I became a liaison for the Foundation, and late that summer I became the Executive Director. Because my CIDP presents acutely I can speak to GBS patients just as well as to CIDP patients.

We are rare disorders, 1 to 2 in 100,000 for GBS. All our volunteers are either patients or caregivers of patients. We have 32 liaison volunteers across Canada and our patients are our biggest source of information. The Foundation builds relationships with doctors and specialists, and we make connections and provide information about services, best practice, challenges, and activities.

I have observed that a common denominator of people developing these disorders is that they tend to be type A personalities – these are people involved in a lot of activities, with busy lifestyles and careers. When you develop a condition such as GBS or CIDP it's as if a big hammer falls down on you. It is a warning bell that puts everything into perspective. Some of us listen; but truthfully, it's hard to change your personality. Now when I am exhausted I listen to my body. I lie down to get a quick rest to get through the rest of the day.

One of the biggest challenges facing patients with these conditions is that not enough emphasis is placed on the management of residuals. Once a patient has either been treated for GBS or has achieved stability with CIDP, many of us are left with after effects that are difficult to manage. After GBS you may be left with permanent physical limitations – you could be in a wheelchair. Imagine you are a plumber and now you are in a wheelchair.

You have to accept that your life has changed. You have to go through a mourning of what you were once able to do. You must come to terms with the new reality and adapt what you can do physically. It is difficult when you still have to walk with a cane, or you still have major amounts of pain. How do you maintain a job when you are exhausted? The consequences of GBS could mean you have to change your career. Or you could find yourself struggling with family life because some people just don't know how to support a loved one who is ill.

We used to be carefree. Now I have a husband who worries about me and two little girls who make sure I am constantly checking in and reassuring them I am okay. Every time you get flu you wonder if you will have a relapse. I don't want to be on treatment if I don't need to be, but every time I get hit with one of these acute relapses I don't know what is going to be recoverable. When you relapse it takes a lot of willpower to get through it. Every time I relapse it becomes harder to deal with. A lot of patients deal with depression.

The Foundation is committed to ensuring that no one with GBS or CIDP suffers alone and that everyone has access to treatment. We are a foundation run by patients for patients. We are here to support and every day we are continuing to get better at what we do. Doing this work, I have met fantastic people from all walks of life. Their courage is inspiring.

IVIG saved me and for this I am grateful. Experiencing this condition, you discover a sense of your own mortality. I have seen my mortality more than once. After coming through that you hug your kids more often. You tell your family you love them more often. You take one day at a time and you appreciate that day. You live life to the fullest. I want to thank Octapharma for the chance to tell my story, our story.

WATCH PATSY'S VIDEO
annualreport.octapharma.com/patients

THERE IS ALWAYS TIME IN LIFE FOR AN ADVENTURE.

PATSY, 71
CORNWALL, UK

I am living an interesting and varied life. In my youth I travelled the world and spent several years working overseas doing many different jobs; I didn't specialise in one thing. I feel as if I really lived before starting married life. I had seen and done a lot already and marriage was the next step. Women do it all the time now, but back then in the 1970s it was unusual to start a family in your thirties.

When I was 45 years old I was diagnosed with chronic lymphocytic leukaemia (CLL). My sons were young (6, 8 and 10) so it was shocking to find out that I had an incurable chronic disease. When I was first diagnosed the consultant told me that, although she couldn't cure me, her job was to keep me healthy until such a time when new drugs were developed that would suit me. I trusted her and stayed with her for 25 years.

My journey has not been straightforward. I have been through very difficult times. I had to have chemotherapy. I almost died when I had my gall bladder removed and it went badly wrong – my platelet count was so low they couldn't stop me bleeding. My eldest son, a doctor, who was working in New Zealand at the time, had to fly home because they thought I was going to die. It wasn't easy, but I survived and kept on going.

It had always been our dream to design and build our own home. We bought a plot of land in Looe in Cornwall. It is a traditional seaside town with a strong fishing industry and lots going on throughout the year, including music and literary festivals. The land we bought overlooks the river estuary, on one side you see the town's sparkly lights, and opposite you see the woods and their changing colours. It wasn't the simplest house to build – it's on a 45 degree slope – which presented a challenge for my husband, who used to work in construction. I did most of the interiors because I have experience of interior design. The house was built within eight months, which was surprisingly efficient. That project was a big adventure, and the outcome is wonderful: we love our home.

Before moving here we had lived in the same village for 25 years. At first people were concerned about my health when I told them we were moving. Living with leukaemia for so long, my immune system had deteriorated meaning I was susceptible to infections. I was given immunoglobulin intravenously in the winter as that was when they thought I needed protection the most. I would often get sick because my immune system was not fighting infections properly.

When we moved to Cornwall three years ago, I expected I would continue with my seasonal immunoglobulin boosts in winter. However, unlike my former hospital, Derriford Hospital has a dedicated immunology department. I was referred to an immunology consultant, who did lots of blood tests. She rang me on Christmas Eve and asked me to come to the hospital. She explained that my immune levels were very low and I needed to start weekly intravenous immunoglobulin therapy.

My immunology team are amazing: they are warm, helpful and kind people. I can ring them whenever I want. There are all sorts of people treated at the centre from a spectrum of generations – from youngsters to elderly people – all there for a variety of reasons and all of them in good hands.

I was asked if I wanted to take my immunoglobulin subcutaneously at home rather than come to the clinic every week. Home therapy opened up new possibilities of freedom and travel. My nurse, Teddie Trump, showed me how to infuse myself and after visiting the centre every week for six weeks I was ready to infuse at home. Teddie visited my house to watch me infuse and make sure I was confident in what I was doing.

The switch from intravenous to subcutaneous treatment has given me real independence. I take care of my treatment myself. Since I started three years ago my health has improved and I have had only one episode of pleurisy. People should not worry about doing infusions themselves at home – it gives you so much freedom by removing that elastic band that connects you to the hospital. It's wonderful – whoever invented it deserves an award. It is no exaggeration to say that gammanorm® has changed my life.

"People should not worry about doing infusions themselves at home – it gives you so much freedom by removing that elastic band that connects you to the hospital."

Now I just go to the immunology centre for an annual check-up, and for the leukaemia I see my haematologist every three months. We are very lucky in the UK; I cannot begin to praise the National Health Service enough. If it wasn't for the NHS I might not be alive today.

My greatest passion in life is sailing and since my husband retired we can spend more time on our yacht, which we share with friends. I don't do grey, lumpy, stormy water; I prefer to sail calm seas under a shining sun. Last summer we spent nine weeks sailing around the Greek islands. It is amazing to think I am going on these adventures without a care in the world 26 years after being diagnosed with leukaemia. It's an idyllic life. Sailing is the best way to explore the Greek islands, which are all beautiful, each in their own unique way. Even planning the route is an adventure because you have to wait until the wind changes. I take my gammanorm® with me on these voyages and store it in a little pink fridge underneath the chart table where we do our navigation planning.

Before I started home therapy, I had to think twice about doing anything because I was always tied to the hospital. Now I don't have to think twice about it; wherever I am I infuse myself once a week and I know that I am protected. I have a belt which allows me to infuse while walking about or gardening, but I prefer putting my feet up for an hour to read a book.

I am a very positive, happy and active person. Apart from sailing, I do a lot of walking with my dog and I like keeping fit – I do Pilates. I'm creative: I like painting, I belong to a flower arranging club, and at the moment I am renovating an intricate old lamp. I enjoy socialising, cooking and hosting dinner parties. I also love spending time with my wonderful grandchildren. Life is there to be enjoyed and I believe there is always time in life for an adventure.

ONE SIZE DOESN'T FIT ALL, EVERY PATIENT'S JOURNEY THROUGH LIFE IS DIFFERENT.

TEDDIE TRUMP,
CLINICAL NURSE SPECIALIST IN IMMUNOLOGY,
PLYMOUTH HOSPITALS NHS TRUST, UK

I look after immunodeficiency patients on immunoglobulin replacement home therapy.

When someone is diagnosed with an immunodeficiency they are often relieved to finally know the reason why they have been so ill for so long. After diagnosis they must come to terms with the fact that they have a chronic illness and will need treatment for the rest of their life.

I have 90 patients in my care and get to know each one well; it's a lifelong relationship. We tell newly diagnosed patients about the immune system and explain what immunoglobulin replacement therapy involves. There are two main types of immunoglobulin administration: intravenous (into a vein) and subcutaneous (under the skin).

One size doesn't fit all because every patient's journey through life is different. You have a spectrum of patients, from the teenager struggling to accept that they have this condition and seeing it as a weakness, to the elderly person struggling to get to hospital for their infusion. Treatment also needs to be adaptable to changes in lifestyle. You have to look at every patient individually and find the right approach that works for them.

If subcutaneous treatment is selected, we teach the patient how to administer treatment themselves at home. We show them how to use the syringe and how to insert the needles. We go through everything, from the importance of cleanliness to the logistics of how products are delivered to their home. We take time with patients so that by the time they go home they are feeling very confident and happy. I love it when I do a home visit and I can see that the patient is so happy to be at home. I love knowing that treatment will just slot into their life, rather than them trying to slot their life into an infusion schedule.

In our clinic there is a picture of Patsy infusing gammanorm® while she is on her yacht. This is really inspiring and helps our new patients see that they can have that freedom too.

WATCH LISA'S VIDEO
annualreport.octapharma.com/patients

I'M LUCKY TO BE ALIVE.

LISA, 47
CHILD MINDER,
WEST MERSEA, UK

I was at work and I started to feel pins and needles in my arm and on the left side of my body. My mouth started to droop. I later found out that I was having a mini stroke.

It had all started a few weeks earlier when I began to feel extremely tired and unwell. The whites of my eyes had turned yellow and I had one instance of blood in my urine. The doctor thought it might be anaemia but the blood test results didn't come back in time.

What happened at work was very scary but thankfully my colleagues responded quickly and called an ambulance immediately. I was taken to the accident and emergency (A&E) department of Colchester General Hospital. They thought at first it might be a migraine. I was admitted to A&E and throughout the day my symptoms were getting increasingly worse. I was having blood taken when I began to have a seizure. At this point my memory goes blank.

The next thing I remember is waking up and seeing very bright lights. I was confused and didn't know where I was. I had no memory of being transferred to University College London Hospital (UCLH) by ambulance. I was in the Critical Care Unit.

"The nurses were very kind and patient with me. They had to tell me again and again that I had something called TTP (thrombotic thrombocytopenic purpura) and that it was very serious."

The nurses were very kind and patient with me. They had to tell me again and again that I had something called TTP (thrombotic thrombocytopenic purpura) and that it was very serious. I just could not believe that it was all that bad because I was feeling so much better than I had done for weeks. I had also woken up rather bizarrely with a strong cockney accent. I was finding everything very funny and was constantly making jokes, although in hindsight what was happening to me was not funny at all.

TTP is such a rare condition that it is almost unbelievable to think that I have it. But it happened. I am lucky that the haematologist at Colchester General Hospital knew about this rare condition; if he hadn't reacted so quickly and got me transferred to the specialist centre, I might not be alive today.

I was in Critical Care for a few days, then later was given my own private room with a beautiful view over London. My treatment involved plasma exchange, which is a true miracle machine. For hours at a time I was hooked up through needles in my neck while my plasma was taken out of my body and replaced with other people's plasma. I went through this process again and again, until my platelet count returned to normal. I was at the hospital for two weeks. It's almost like a top hotel, and all the staff are so caring, kind and friendly. My consultant, Dr Marie Scully, and all the staff know you by name. Despite the circumstances of my stay, it is a lovely place to be. You feel as if you are the only person who is ill.

This whole experience has been very traumatic for me and my family. My mum, who is 70 years old, could not get her head around what was happening, which was made worse by the fact it was hard for her to visit me when I was at the hospital in London. My daughter, who is 13 years old, was on holiday in Florida with her father when I became ill. My mum had to wait for my daughter's plane to land before calling her to tell her I was unconscious in Critical Care.

"I was recently at a patient event and met one of the transfusion laboratory staff, and when I told him my name he said: "I know your blood!" He hadn't met me but he knew my story!"

After what happened my daughter didn't want to leave me or let me go anywhere. She was scared that something would happen again. That's the awful thing about it – they can't say whether or not I will have a relapse.

The TTP Network is a patient group set up by patients to support patients and their families. As TTP is so rare, it is great to meet other patients who have been through something similar to you – you form a strong bond straight away. The more people who know about this condition the better. Nobody I knew had heard of this before it happened to me. As patients, we want to know why we got TTP and if we will have a relapse. I attended a recent TTP patient day in London, and it was so lovely to see a lot of staff from the hospital there too; they had given up their free time for us, they really care. Many of us also took part in a sponsored walk for TTP Education & Research during UCLH's 2016 London Bridgathon, which raises money and awareness for the condition. I met one of the transfusion laboratory staff from the hospital, and when I told him my name he said: "I know your blood!" He hadn't met me before but he knew my story!

It's difficult to come to terms with living through a near death experience. I had to take three months off work and it took time to recover physically. Many of the patients I've met have experienced side-effects after TTP, such as depression or extreme tiredness, but I haven't experienced any. I live a perfectly normal life now. I have a very physical job as a childminder for very young children so I'm never sitting down. I suppose I have reacted relatively positively to what happened. I know I'm one of the lucky ones to have survived this. I am a much happier person than I was before this happened. I just feel so grateful to be alive. I believe more than ever that you should live for the now.

WE HAVE SEEN PEOPLE COME IN WITH TTP AND DIE VERY YOUNG, VERY QUICKLY.

DR MARIE SCULLY,
UNIVERSITY COLLEGE LONDON HOSPITAL

Thrombotic thrombocytopenic purpura (TTP) is an ultra-rare, life threatening blood disorder that can present at any time in life, usually affecting women aged 30–40. This autoimmune condition causes blood clots to form in small vessels throughout the body and can cause organ damage, e.g. in the brain, heart or kidneys.

TTP can occur very suddenly and people affected often turn up at the accident and emergency department, 10% of them presenting in a coma. We have seen people come in with TTP and die very young, very quickly. Once you've seen that, you don't forget.

A delay in diagnosis can have a massive impact on a patient's risk of dying. Once TTP is identified the patient is given plasma exchange with octaplas®, which acts like a cleansing process removing their plasma and antibodies and replacing it. Plasma exchange is carried out until their platelet count goes up; that's when you see a prompt clinical improvement. Before plasma exchange was introduced, there was a 90% mortality rate. Today there is a 90% survival rate. Our priority is to get our patients to survive the acute stage.

Patients often face chronic issues resulting from a frightening near-death experience. They can become anxious and fall into a black hole, resulting in clinical depression. There is a high chance – 30–50% – that a patient will relapse. These people have young families, jobs and partners. Their lives have been seriously disrupted and they live with the fear that it will happen again. TTP is a complete game changer.

University College London Hospital is a centre of excellence for the management of TTP and our objectives are to get quicker diagnosis for patients, improve treatment, and enhance life after TTP, for example by finding ways to predict who will relapse.

With TTP things can go wrong very quickly. We act fast and treat patients as we would want to be treated. We all live by that philosophy. We wouldn't be human otherwise.

ONE IN TEN PATIENTS COMING INTO HOSPITAL WILL REQUIRE A BLOOD TRANSFUSION.

DR JEANNIE CALLUM
DIRECTOR OF TRANSFUSION MEDICINE AND TISSUE BANKS, SUNNYBROOK HEALTH SCIENCES CENTRE, TORONTO, CANADA

One in ten patients coming into hospital will require a blood transfusion. Our centre specialises in the transfusion support of trauma patients, haematology and oncology patients, cardiovascular surgery patients and newborns. We have the largest trauma centre in Canada. When trauma patients come in with massive bleeding, they undergo complex testing so we can find out which coagulation factors are missing. If you give a haemorrhaging patient too little blood they will continue to bleed; however, if you give them too much they will go into fluid overload. The most common complication in transfusion which leads to morbidity or death is transfusion-related circulatory overload (TACO). This happens in patients, usually over 60–70 years old, with heart problems or chronic anaemia. TACO causes heart failure and we see that in 1–3% of transfusion cases.

We were one of the first hospitals in Canada to drive the use of octaplex®, a prothrombin complex concentrate (PCC) which contains clotting factors II, VII, IX and X. When you are on warfarin anticoagulation therapy, your blood is essentially poisoned so that these clotting factors are low. The goal with warfarin is that you don't develop blood clots. If you have a bleed, however, you need an antidote to warfarin. PCCs are used to reverse the effects of oral anticoagulation therapy when bleeding occurs. Before we introduced the use of octaplex® we used fresh frozen plasma (FFP). PCC has been shown to reduce the risk of transfusion reactions, especially TACO, and speed up warfarin reversal time. All our physicians know that we should use PCC instead of FFP; however, on our last audit in 2013 for the Province of Ontario, 10% of our plasma use was still for warfarin reversal despite the availability of a safer alternative. We have now implemented an interceptive process in which, when an order comes in for plasma, the technologists verify if it is an appropriate indication for plasma or for warfarin reversal and, if so, get the physician to change the order to PCCs.

We are currently investigating whether giving fibrinogen concentrate to patients who are bleeding will improve outcomes. Fibrinogen is the first clotting factor and plays a core role in stopping bleeding – it helps your platelets function and is critical to clot formation. In cases of trauma, reduced fibrinogen on arrival increases risk of death. We are trying to determine if the use of fibrinogen concentrates will improve outcomes in severely bleeding trauma patients. We are also investigating if using fibrinogen concentrates after cardiac surgery will result in patients needing fewer red cell transfusions. Fibrinogen concentrate is virally inactivated, unlike cryoprecipitate, and because it is lyophilised rather than frozen it can be used more quickly compared with cryoprecipitate.

I believe that "perfect is the enemy of good". You will never change anything if you get tied up in every minute detail. You have to keep moving forward. Patients should feel confident because there is a massive team of transfusion medicine scientists, technologists, physicians and pharmaceutical partners dedicated to improving bleed management, working very hard every day. There is huge collegiality in this field between different centres and countries. There are thousands of people around the world who are dedicated to driving safety for donors and patients, and passionately working on innovative solutions and improving blood transfusions.

BEHIND EVERY TEST TUBE IS A PATIENT.

KENNETH AMENYAH
TRANSFUSION LABORATORY MANAGER
VIAPATH BLOOD TRANSFUSION LABORATORY, KING'S COLLEGE HOSPITAL, LONDON, UK

It is estimated that 70% of all decisions regarding a patient's diagnosis and treatment are based on laboratory services. Biomedical scientists carry out a wide range of laboratory and scientific tests to support the diagnosis and treatment of diseases. I have the overall scientific and technical responsibility for managing our team of biomedical scientists and scientific assistant technical officers, monitoring the quality of work processes and supporting staff in training, learning and development needs.

In the Blood Transfusion Laboratory (BTL) we carry out blood grouping tests, antibody screening and specialist tests to identify antibodies to enhance the provision of safe and compatible transfusion to patients. In our laboratory we process on average 300 samples each day. We discuss patients with complex or special requirements with clinicians before deciding on the most appropriate blood and blood products for the patient. Indeed, one can refer to what goes on in the BTL as being the 'live wire' of the hospital. Although we do not have direct contact with patients, we never forget that behind every test tube is a patient.

Transfusion refers to the administration of donated blood products such as red blood cells, platelets or plasma. Blood transfusion is indicated in the treatment of various conditions when blood loss has occurred or the body fails to produce enough blood or blood components to meet the body's needs, e.g. bleeding disorders and blood loss due to surgery and traumas. Blood transfusion therapy can be life-saving.

In BTL we store pre-thawed group AB octaplas®LG for trauma patients and ensure timely allocation of this product for bleeding/haemorrhaging patients. We also use octaplas®LG to support patients on therapeutic plasma exchange.

The transfusion of blood components is an important procedure that should only be undertaken when the clinical benefits to the patient outweigh the potential risks. Strict procedures must be followed to ensure that the correct blood component is given and any adverse reactions are dealt with promptly and effectively.

In recent years, many measures have been implemented to increase blood component safety and the safety of the clinical transfusion process. Haemovigilance programmes report the main risks to patients from transfusion. Appropriate use of blood products is a goal worth aiming for.

The success of treating a patient is determined by good clinical judgement, timely intervention and effective communication between the laboratory and the clinical area. It always gives me great pleasure when staff receive good training to fulfil their role within BTL and ultimately enhance patient care.

BLOOD IS ESSENTIAL FOR THE WELLBEING OF EVERYONE.

DR TAREK OWIDAH
CONSULTANT HAEMATOLOGIST
KING FAISAL SPECIALIST HOSPITAL AND RESEARCH CENTRE, RIYADH, SAUDI ARABIA

In Saudi Arabia our greatest issue is the availability of sufficient blood donors to meet the increasing demand for blood products. Unfortunately there is no central blood banking system so each hospital must be self-sufficient and manage its own blood supply through blood donations. I am campaigning for a central blood system in Saudi Arabia. One of my major goals is to see more blood products made available to patients who need them. We set up a charity for haemophilia patients, through which we are helping to raise awareness and campaign for funds and availability of factor replacement products. Challenges make life more interesting.

When a patient needs plasma, they have their ABO blood group validated. The request will go to the blood bank, which will recommend the best product for treatment based on the patient's blood group and the quantity needed. We use fresh frozen plasma (FFP), and for patients with rare blood groups we use octaplas®. The plasma is taken out of the freezer and thawed to body temperature: 37° Celsius.

The most common reasons for plasma transfusions are surgical procedures. Surgeons give prophylactic infusions of plasma to prevent bleeding during surgery. Surgeons are concerned about bleeding during cavity, abdominal, intracranial and orthopaedic procedures. The surgeons tend to be proactive to avoid bleeding, especially during organ transplants. The second most common group of patients with long-term use of plasma are those with rare bleeding deficiencies, such as factor X or II. These patients are prone to bleeding especially with trauma, injury, excessive exercise and surgery. They require regular plasma infusions to increase their coagulation factor levels.

We use a large volume of plasma for the treatment of patients with thrombotic thrombocytopenic purpura (TTP). In our registry we have 100 TTP patients. TTP is a rare, life-threatening condition associated with severe ADAMTS13 enzyme deficiency. It is often associated with renal failure and neurologic manifestations. TTP requires plasma exchange and we usually use FFP; however, when the blood group is rare we use octaplas®. These patients receive large volumes of plasma; for acute patients they can have plasma exchange for anything from five days up to one month depending on their response. We had an interesting TTP case when a young lady in delivery had pre-eclampsia. She had TTP and needed daily plasma exchange for two months. She was AB blood group which is very rare, meaning it was difficult to have sufficient donors to collect enough plasma for her. She was put on 13–15 units of octaplas® daily for two months. For the past year she has been receiving routine supplementation of octaplas®.

Blood products are involved in so many disciplines of medical practice. It is a dynamic and fast-growing area of medicine. The advances in knowledge that have been made during my 18 years of practice have been tremendous. It is a fascinating field and very important because blood is essential for the wellbeing of everyone.

IN HAEMOVIGILANCE OUR GOAL IS TO ENSURE MAXIMUM SAFETY IN ALL ASPECTS OF TRANSFUSION.

BRENDAN BRANIGAN
HAEMOVIGILANCE OFFICER,
BEAUMONT HOSPITAL, DUBLIN, IRELAND

I am a nurse. I worked for over nine years in operating theatres as an anaesthetic/recovery room nurse. I also worked on children's wards, in Intensive Care and as a volunteer in a foreign conflict zone. While abroad, I was often involved in incidents with mass casualties. Today my role includes providing education to doctors and nurses on guidelines in blood transfusion. I am particularly interested in teaching how to manage patients who require massive transfusions due to trauma or other causes. I have been in my current role for 10 years.

Blood transfusion is a complex, fast-changing field of healthcare and that's why education is important to ensure that doctors and nurses have up-to-date knowledge. According to the World Health Organization (WHO), "Haemovigilance is required to identify and prevent occurrence or recurrence of transfusion related unwanted events, to increase the safety, efficacy and efficiency of blood transfusion, covering all activities of the transfusion chain from donor to recipient." The haemovigilance system includes monitoring, identification, reporting, investigation and analysis of adverse events, near-misses and reactions related to transfusion and manufacturing.

In haemovigilance our goal is to ensure maximum safety in all aspects of transfusion. We ensure that nurses and doctors understand the latest guidelines and the measures to avoid risks. Today, plasma is processed to the highest standards available, so we can be confident that patients are protected from being infected with viruses from blood products. However, blood transfusion has some inherent challenges simply from the fact that a patient is getting transfused with a biological substance that comes from another human. Part of my role is to investigate suspected transfusion reactions, which fortunately are rare and usually mild in nature.

Some patients really have no idea of the benefit they have gained through the science of blood transfusion. They may be completely oblivious to it. They might be informed by their doctor or nurse: "We had to give you ten pints of blood" – if only they knew it was much more complicated than that!

A few years ago, while kayaking in Stockholm, I was surprised to see the 'Octapharma' sign over a building, and this chance encounter led to a fascinating visit to one of Octapharma's production facilities. I learned a lot about plasma fractionation there, as well as the interesting history of plasma production in Stockholm.

I have many international contacts in the field of transfusion. We help each other and share knowledge and experience. Blood transfusion is a fascinating field of healthcare, and I really enjoy teaching and bringing new ideas to my hospital which benefit patients.

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- Octapharma Global HQ
- Octapharma Plasma Inc. HQ
- Octapharma locations
- Production sites
- Plasma donation centres

- Patients treated with our products
- Haematology stories
- Immunotherapy stories
- Critical Care stories

Vision: Our passion drives us to provide new health solutions advancing human life.

Values:

- Ownership
- Integrity
- Leadership
- Sustainability
- Entrepreneurship

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We are passionate about making a difference to patients' lives around the world and understand local healthcare challenges.

IMAD ISSA
OCTAPHARMA REGIONAL SALES MANAGER, GULF COOPERATION COUNCIL FOR THE ARAB STATES (GCC)

When I joined Octapharma in 2002, our strategy in the region was to promote the concept of quality for plasma products and differentiation between the available brands for the benefit of patients in terms of efficacy, safety, commitment and availability. We launched an educational initiative for doctors and pharmacists throughout the region called the Plasma Quality Program. The objective of the program is to increase awareness of best practices in plasma products and the international guidelines for the selection of high quality products. The program is approved by the Council for Health Specialists and participants are credited with continuing medical education (CME) hours.

The major trend of the countries in the GCC region for plasma products is the tender market. There is a large tender which covers the demand for these products in Saudi Arabia, the United Arab Emirates, Kuwait, Oman, Qatar and Bahrain. We were successful in improving the guidelines of this tender by implementing international quality standards, which has had a very positive impact on patients.

The greatest challenge in the region is availability of plasma products to fulfil continuous increases in demand. In 2013, Saudi Arabia's Ministry of Health (MOH) added octaplas®, our pharmaceutically licensed, standardised solvent/detergent treated human plasma, to its Central Formulary of Pharmaceutical Products, allowing us to sell octaplas® to all MOH hospitals. This is of great value for patients because it provides them with a reliable and continuous supply of octaplas® with all the clinical advantages it has over single donor fresh frozen plasma (FFP). This is especially important in treating thrombotic thrombocytopenic purpura (TTP) and factor V deficiency patients.

I feel for the families and the people who require plasma products. Just like bread, food and water, these products are essentials for life. Imagine you are a parent and you give your son a home, you provide food and water for him. You give him all he needs to live and be healthy, but there is something essential which you cannot give him. Without plasma products lives can become very miserable.

Just before the Eid holiday, I received a call from a mother of a child with haemophilia B. The boy had returned from school with bleeding in his knee. The mother was crying. She was desperate – she needed factor IX for her son. As a human being, when you get a call like that there is nothing else you can do except drop everything and work hard to secure the medication. Understanding the urgency of this case, we immediately began coordinating a solution and instructed the mother how to acquire octanine®F for her son.

Later that night, the mother sent me a picture of her son and he was laughing. I felt so happy knowing that the patient was doing well. In this region haemophilia is treated on demand rather than prophylactically. I believe that introducing prophylactic and home therapy treatment will greatly contribute to a much higher quality of life for all haemophilia patients. When I look at that photo of the boy laughing, I feel that I really did something good. The mother was not in the picture, but I am sure that she was happy and smiling too.

DR CHEN XUYU M.D.
OCTAPHARMA COUNTRY MANAGER, CHINA

Since 1986 Chinese government policy has forbidden all blood and plasma-derived products from being imported into China, with the exception of human albumin. This three-decades-long ban was a response to four cases of HIV infection caused by imported factor VIII (FVIII), detected in 1983. Today China has around 25 domestic plasma fractionators supplying plasma-derived products, such as immunoglobulin and coagulation factors, to its population of 1.4 billion people.

Despite its embargo on foreign imports, China is not self-sufficient in plasma products. In China plasma collection is forbidden in the big cities and takes place only in rural areas. There is some stigma attached to donating plasma. Recently Chinese domestic fractionators launched campaigns to educate the population and explain how plasma donations can help save many people's lives.

In China there is a huge demand for albumin with approximately 50% of that product being imported. Albumin is widely used in Chinese hospitals and is a critical component in saving lives. It is used mostly in critical care or emergency situations when people have traumatic injuries and burns. It is also used in the treatment of gastrointestinal conditions and liver disease.

Each year Octapharma supplies China with large volumes of its human albumin product albunorm®, the majority of which is produced in our Vienna production site. In 2016 we also started producing albunorm® for China in our Stockholm production facility.

The China Food and Drug Administration (CFDA) introduced a policy that every medical product requires serialisation. China is the first country to introduce the system, which aims to improve the traceability and classification of medical products. Each packaging level, from carton to pallet, is furnished with a unique serial number. Serialisation enhances patient safety and product traceability, making forgery of medicine and the illegal intermediary trade business more difficult. While China is the forerunner, more and more countries are enhancing protection against forgery. A multidisciplinary team, including experts in artwork, IT, packaging and production, collaborated to implement these track and trace systems in our Vienna and Stockholm production sites.

I hope that in future the Chinese government will lift its ban on importing plasma-derived products into China. Today Chinese patients with haemophilia experience shortages of plasma-derived coagulation products. Some patients have died as a result of not having access to treatment. The government eventually agreed to allow recombinant coagulation factor products to be imported to make up for the shortage. Octapharma is currently conducting a clinical trial in China for its human cell line recombinant FVIII Nuwiq®.

There are many challenges in the Chinese market, but there is a Chinese proverb: "Where there is a will there is a way." We will continue to work hard to advocate, educate and try to influence change in China and its approach to supplying patients with these lifesaving medicines.

ABEL FERNANDES
OCTAPHARMA VICE PRESIDENT, LATIN AMERICA

In 2012, Octapharma established the "Red Lapi Network", which comprises 14 physicians each representing a different country. The network meets twice a year in different cities of Latin America (LATAM) to discuss challenges and best practices, and develop strategies to improve the situation for haemophilia patients.

LATAM is a diverse landscape when it comes to healthcare. Countries such as Argentina, Colombia, Chile and Uruguay have very sophisticated healthcare systems. They have very effective haemophilia treatment programmes with robust diagnostic infrastructure. In other LATAM countries, there is a lot of work to do in diagnosis and treatment programmes. Looking at the recent 2015 World Federation of Hemophilia (WFH) Global Survey report, there is a need for improvement in education and best practice. Several countries reported a very low consumption of factor VIII (FVIII) product, below 1 IU per capita. Furthermore, we can see very poor diagnostic programmes in the other countries.

Patient associations also have a key role to play in advocating on behalf of patients to convince the authorities that these diagnostics and treatments should be introduced. They will continue to raise awareness of new concepts of treatment and best practice based on WFH's recommendations.

The LATAM division of Octapharma represents all countries of Latin America, including Central America and Caribbean countries, excluding Brazil and Mexico. Octapharma has been operating in LATAM for many years, initially managing activities from Europe. In July 2014, Octapharma established its representative office in Panama, which has allowed us to develop stronger ties with our distributors and key stakeholders in the region. We have developed many workshops and "Octa Academy" meetings in the most relevant therapeutic areas, with many healthcare practitioners taking part in these scientific training courses.

Octapharma has been strengthening its business in the LATAM region, and in the last three years has achieved sales growth of over 20% per year. With a strong market share position in the coagulation products octanate® and octanine®F, we also have significant reinforcement in products such as albunorm®, octagam® 5% and 10%, and the prothrombin complex concentrate octaplex®.

During 2016, Octapharma launched its human cell line recombinant FVIII Nuwiq® in several countries: Colombia, Paraguay, Ecuador, Chile and Guatemala, with upcoming launches planned in Argentina and Peru. We expect to launch Nuwiq® in the remaining LATAM countries during 2017. Now we are working towards obtaining registration of Octapharma's new intravenous immunoglobulin (IVIG) product panzyga®, and hope to launch this during 2018 in the most important markets in the region.

For me, working in a completely different pharmaceutical and sociocultural environment has been an enormous and exciting personal and professional challenge. The LATAM team is based in Panama but is supported by many people around the world. To sustain our leadership and continue to grow in this niche biopharmaceutical market, we must enhance support and collaboration with our local partners to implement and develop scientific meetings/workshops with key stakeholders in the region. There are many areas for future development and investment, including the introduction of new products and better product access contributing to an improvement of patients' quality of life.

DR KATHARINA POCK
OCTAPHARMA SENIOR DIRECTOR, RESEARCH & DEVELOPMENT (R&D) PLASMA

Within R&D Plasma my group is responsible for the preclinical development of novel plasma-derived therapeutic protein products as well as the life cycle management of the established plasma product portfolio, focusing on regulatory, production and marketing topics. One of our key objectives is to ensure that Octapharma is optimally using every drop of its precious raw material – human plasma.

I completed my PhD thesis on factor VIII characterisation with Octapharma in 1998, and have been employed with the company since then. In the characterisation of plasma proteins one elucidates the structure of the protein. The goal in purification is to separate and protect the specific protein while optimising product yield. The integrity of the protein has to be maintained throughout the process because the resulting purified plasma component will, ultimately, reach our patients. The protein has to be pure, active and as close to its native state in plasma as possible. Using various analytical techniques, including chromogenic and potency assays, we analyse and profile the structure and properties of the purified plasma protein.

There are so many proteins found in plasma, with different concentrations, molecular weights, half-lives and stabilities. This is a fascinating field and I am proud to be in a position that combines science with the management of people. It is very rewarding to work together on scientifically challenging areas in order to develop products that save lives. We can make a real difference to quality of life, for example by developing new applications for existing products to improve convenience and allow patients to be more independent. This is especially important when it is considered that many of our patients need lifelong treatment.

One way of improving convenience for patients is by developing a product with a reduced volume for intravenous administration, or a subcutaneous application for an existing intravenous product. When embarking on such a project, there are various factors to consider. The formulation of a subcutaneous product must be more concentrated compared with the intravenous product because one cannot infuse a large volume subcutaneously. Therefore the protein must be stable in higher concentrations. We must also ensure that the active ingredient is not degraded when applied subcutaneously.

In March 2016 we held the ground-breaking ceremony for our new R&D centre in Vienna, which will be home to my R&D Plasma group and the Clinical Research & Development (CRD) department. The building has a net floor space of 4,500m^2 and consists of six floors with 13 laboratories (1,600 m^2) and 39 offices (1,200 m^2), accommodating around 100 people – 60 from R&D and 40 from CRD. We have been in our current location for 18 years, so the new building had to be planned with a long-term view considering what the future needs will be, especially as Octapharma continues to grow. The investment in our new home shows Octapharma's long-term commitment to R&D.

Our donors transform lives by giving their plasma so our patients can be treated with life-changing medicine.

SHERRY, 60
PINEVILLE, NORTH CAROLINA

Sherry is a great-grandmother, seamstress, tax professional and long-time Anti-D plasma donor. She runs her own tax company and for the past 40 years has donated plasma twice every week, even during the busy tax season. She spends the hour it takes to donate reading on her Kindle and relaxing.

Sherry first learned about donating plasma after her second son was born. As an Rh negative mother she was at risk from complications during pregnancy. She didn't know much about the Rh factor at the time, but learned that a plasma-based treatment during her pregnancy was necessary to prevent harm to her developing child. She says: "I am truly grateful for that treatment and for the health of both my babies."

She donates to help give mothers a better chance of having safe, full-term pregnancies and healthy babies. She encourages everyone in her family to donate plasma, even her son who is currently serving in the army. Sherry believes her plasma donations, and her personal story, are the most important things she can share with others.

MARK, 48
MILWAUKEE, WISCONSIN

Mark learned about the life-saving benefits of plasma donations when he served in the Marine Corps during the Gulf War. In May 2016 he read that an Octapharma Plasma donation centre had opened nearby. A single father, he began donating at the centre to help others while also earning money which he could put toward his daughter's confirmation.

To reach his donation centre Mark travels by bus on a two-hour round trip. Including time for the donation process, each trip takes him about three hours. Originally, since it was such a time commitment, Mark planned only to donate until after his daughter's confirmation. However, he decided to continue donating once he learned how many people could benefit from his regular donations. To this day Mark still makes the three-hour trip to donate twice every week.

Mark donates plasma because it helps give patients medicines that can change their lives. He says: "Plasma isn't made in a lab, and this is an easy way for me to help others. Donating plasma is one of my favourite ways of giving back."

OUR VIRUS INACTIVATION STEPS WERE PROVED TO BE SUCCESSFUL AGAINST ZIKA VIRUS.

DR DENIS KÜHNEL
OCTAPHARMA STUDY DIRECTOR, VIRUS & PRION VALIDATION, OCTAPHARMA, FRANKFURT, GERMANY

On February 1st 2016, the World Health Organization (WHO) declared Zika virus (ZIKV) a public health emergency of international concern. The scientific consensus is that Zika virus, a mosquito-borne flavivirus first identified in humans in 1952, causes neurological disorders including microcephaly and Guillain-Barré syndrome.

Octapharma's Virus & Prion Validation group in Frankfurt responded quickly by planning and executing studies to validate our existing viral inactivation/elimination processes against Zika. Octapharma uses a variety of dedicated viral inactivation and removal steps in our fractionation processes in order to ensure the viral safety of our plasma-derived products. For an enveloped virus, solvent detergent (SD) treatment is still, some three decades after introduction by Octapharma, the current gold standard in inactivation. For a virus larger than 20 nanometres, nanofiltration removes the virus.

As ZIKV is an enveloped virus SD treatment or pasteurisation are highly effective in inactivation, and as it is larger than 20 nanometres, nanofiltration is effective in eliminating it. Despite having the theoretical knowledge that our existing production processes will inactivate and remove the virus, it was important for us to demonstrate this scientifically and validate that our production techniques are successful in inactivating ZIKV.

Our whole scientific team was involved in the Zika studies. In a biosafety-level laboratory the safety measures were scaled down and the virus was added to intermediates of the respective production process. The viral inactivation techniques of SD treatment and pasteurisation (60°C) were applied, then we determined if the virus titre was below the detection limit and if the virus safety steps were sufficient to inactivate ZIKV. We completed studies for four Octapharma products, then analysed and collated the results from February until June 2016. The findings were very satisfying as our well-established virus inactivation steps were proved to be successful against ZIKV. The study results have been published in the "Transfusion" journal.

In our routine work we perform virus and prion validation studies for all Octapharma products, both plasma and recombinant, as well as new development products in the pipeline. We verify the efficacy of the viral inactivation or removal methods used in our production processes by performing Good Laboratory Practice compliant studies on a laboratory scale. In our studies we use samples of Octapharma products from the different production sites. In our labs we add to product intermediates various viruses, including human immunodeficiency virus (HIV), West Nile virus (WNV) or hepatitis A (HAV), in order to perform our validation studies.

I know many people who don't like to work in a biosafety-level laboratory but I enjoy it. I am fascinated to know that we are handling dangerous viruses which can cause fatal diseases. I am very proud to be part of a team which is responsible for the viral and prion safety of Octapharma's products. Viral safety was the idea upon which Octapharma was founded. Our viral safety steps mean that no patient has to fear being infected with viruses from our products. I am proud to see our products helping so many patients all around the world. Mark Twain said: "Give every day the chance to become the most beautiful day of your life," and I try to live up to this every day.

DONATING PLASMA HELPS ME PURCHASE BOOKS FOR ALL MY CLASSES.

JAMIE, 23
MILWAUKEE, WISCONSIN

For years, Jamie's grandmother relied on the life-saving donations of strangers to maintain her health. Jamie started donating in her late grandmother's honour to help others in similar situations. Jamie says: "If plasma donations weren't used for a good cause, I probably wouldn't donate. I enjoy helping people, even if I don't know them."

Currently a student at the local university, donating plasma helps Jamie purchase books for all her classes. She works full time in a retail chain store corporate office, and is studying Supply Chain Management and Marketing to help further her career.

Jamie donates plasma after work at least once a week. While donating she listens to music, scrolls through Pinterest, and plans her photography, scrapbooking and other craft projects. Jamie says: "Donating isn't a big time commitment, it's easy and it's not painful. Every time I donate I'm impressed by Octapharma's clean facilities and friendly staff."

AMBER, 31
MILWAUKEE, WISCONSIN

Amber is a single mother who has donated with Octapharma Plasma for about eight months. She started donating because she wanted a way to fund vacations with her daughter, and liked the idea of being able to make money while making a difference.

Amber researched several plasma companies before she started donating. Once she found Octapharma Plasma's website, she became comfortable with the donation process, confident that donating was safe and positive she'd found her donation centre. Amber donates during her lunch break once or twice every week. She finds the overall donation experience very relaxing because the staff are always extremely conscious of both her time and health. Donating plasma fits easily around Amber's full-time job, and also lets her focus on family time with her daughter. In 2016 she used the money she made from donating to take her daughter to Walt Disney World.

As part of her job Amber works on a health and wellness committee. She constantly educates and encourages her colleagues to donate, saying: "Don't be scared to donate, because it's great to be directly helping patients in need of plasma products, and at the same time earning some extra money."

DONATING PLASMA EASILY FITS AROUND MY FULL-TIME JOB, AND ALSO LETS ME FOCUS ON FAMILY TIME WITH MY DAUGHTER.

WE PERFORM TESTS ON EACH AND EVERY PLASMA DONATION COLLECTED IN OUR CENTRES.

MONICA BYRD
OCTAPHARMA PLASMA INC. (OPI),
SENIOR DIRECTOR REGULATORY AFFAIRS
& QUALITY ASSURANCE

At OPI in the US we collect, test and supply human blood plasma for the manufacture of Octapharma's lifesaving medicines. All OPI plasma collection centres are licensed by the relevant national health authority, and are operated in compliance with EU and/or US Food and Drug Administration (FDA) Good Manufacturing Practice (GMP) and the quality and safety standards of the Plasma Protein Therapeutics Association (PPTA).

My team is responsible for regulatory affairs and quality assurance for OPI. In partnership with the operations teams in our plasma collection centres, we ensure that our business and products are compliant with the regulations and that we are operating in the most efficient and compliant way. Looking at the business in totality and working together with different functions to find solutions is the fun part of my job.

The quality systems and best practice templates in place guarantee a consistent level of information and integrity of our processes for our existing and newly opening plasma centres. We believe that quality should be a habit, not an act. And we are even more conservative when it comes to safety because we have a responsibility to our business, to our reputation and, ultimately, to our patients.

To ensure the product quality and safety, we perform tests on each and every plasma donation collected in our centres. We screen for the presence of specific blood-borne viruses, such as human immunodeficiency virus (HIV), hepatitis B (HBV) and hepatitis C (HCV). The plasma is physically held and electronically quarantined until successful test results are confirmed. Only then will the plasma be shipped to our European production sites to be manufactured into medicines.

OPI is in a growth phase. We have 73 plasma donation centres as of the end of 2016, and plan for 82 by the end of 2017. In August 2016 we received approval from the US FDA for our new state-of-the-art viral testing laboratory in Charlotte, North Carolina. Bringing our plasma viral testing in-house gives us more control over our processes, and will also enhance our ability to expand operations.

Patients are always in our mind and I believe that quality is everyone's responsibility, regardless of whether or not the word is in your job title. I experienced a big eye opener when I met someone in my personal life who told me she was a recipient of plasma therapy. I had advertised for a babysitter and one of the candidates told me that she has a chronic illness and has immunoglobulin infusions on a weekly basis. Meeting a person who relies on plasma products touched me very deeply. It brought home the importance of what we are doing every day, supplying safe plasma which is manufactured into lifesaving medicines for our patients all around the world.

TJ, 24
BROOKFIELD, WISCONSIN

Three years ago TJ attended art school for photography and advertising. He recently began attending a local technical college for a degree in IT. After several years of schooling, he has built up some student debt. Two years ago a friend recommended TJ start donating plasma as a resource for extra money.

He says: "Donating plasma does more than you think it will to help others, and at the same time you have a little extra cash in your pocket. I've donated with several plasma companies, and Octapharma Plasma is the cleanest, most smoothly run, and highest calibre facility I've seen." During one of TJ's donations at Octapharma Plasma an employee talked to him about applying for a job. He put in an application that day and was later interviewed and hired. He has been a floor technician with Octapharma Plasma for seven months, and plans to continue working and donating there.

TJ believes Octapharma Plasma employees treat donors like a community. His favourite part about donating plasma and working at a donation centre is the opportunity he gets to meet new people and talk to them, learning about each person's individual experiences.

OCTAPHARMA PLASMA EMPLOYEES TREAT DONORS LIKE A COMMUNITY.

LIKE MANY PLASMA DONORS, MY LIFE HAS BEEN PERSONALLY IMPACTED BY PLASMA DONATIONS.

ANGIE, 41
KIRKSVILLE, MISSOURI

Angie is a wife and mother of four children, and her days are extremely full. She donates plasma because it is flexible, like a part-time job. The money she makes through plasma donations covers her family's travel, date nights, and a variety of other "needs and wants". Donating lets Angie contribute to her family's budget while still focusing on her children.

Angie likes the atmosphere of Octapharma Plasma because she gets to visit with employees as well as take "personal time". Donating gives her time to check emails, read, and enjoy a peaceful respite from an otherwise busy day. She tells her friends and family: "Don't be afraid to donate, even if you're nervous around needles. The staff care and the donating process is so smooth, I don't even realise I'm doing it half the time. It's just not that big a deal."

Like many plasma donors, Angie's life has been personally impacted by plasma donations. She is Rh negative and received treatment with each of her pregnancies, and her cousin receives plasma-derived medicines for a lung disease. Knowing real patients makes donating plasma extremely meaningful for Angie.

OUR PATIENTS DEPEND ON US DOING OUR JOB IN THE BEST POSSIBLE AND COMPLIANT WAY.

MICHAEL SZKUTTA
OCTAPHARMA, HEAD OF CORPORATE QUALITY PLASMA (CQP)

Most of our medicines are derived from a human-sourced raw material – human plasma – and it is essential that we have robust, compliant and fully traceable processes throughout the entire production. Each year Octapharma handles 5.6 million litres of plasma collected by 300 plasma suppliers.

Our goal in CQP is to ensure regulatory compliance of all our external and internal processes, from the point of collection at our plasma suppliers until the plasma is released for production. My group's responsibilities include auditing and qualifying Octapharma's plasma-related suppliers and maintaining our Plasma Master File (PMF), which is the compilation of all the required scientific and regulatory data on the quality and safety of human plasma.

In 2016 we established Octapharma's CQP function, which is responsible for all plasma-related quality activities. Previously the function was set up with local quality assurance plasma departments reporting into the local quality units. The corporate approach now allows possibilities for more harmonisation of our internal processes across all sites.

We have a clear understanding of the requirements dictated by regulations as well as our business needs, and we must communicate these effectively to our suppliers, which include plasma donation centres, blood banks, testing laboratories, transport companies and warehouses as well as our internal partners.

We conduct regular audits of about 500 suppliers to ensure they are working according to the mandated procedures and regulations. When we are auditing a plasma supplier we always try to include the processes for a completely new first time donor. We follow the entire donor flow from the moment the donor first registers, right through to when they leave the centre. We also look at the relationship between the staff and donors by observing how the donor centre staff behave towards the donor.

Our patients depend on us doing our job in the best possible and compliant way. Good manufacturing practice (GMP) is the world my team and I live in. These are the regulations that we follow to be compliant. As employees, we all have a responsibility to raise our hands if we recognise that something is not done in the right way. We have a duty to our patients.

Some countries have restrictions on plasma origin for their final products; therefore we must ensure that these products are made from the correct plasma source. This is ensured through robust traceability systems. If a plasma supplier is located outside of Europe and we want to use that plasma for European products, we need to ensure the supplier is approved by a European authority. For that reason we work very closely with the Austrian Agency for Health and Food Safety (AGES), which carries out the inspections in our US plasma donation centres.

Our objective in CQP is to sustain the high level of quality we have built up in correlation with our plasma suppliers in our internal processes, to ensure safety and tolerability for products and patients. Our patients cannot visit our manufacturing sites or our donor centres personally, so they rely on us. I am proud to know that my group and I are playing this important part in fulfilling our responsibility to our patients.

A strong performance keeps us on track for advancing human lives.

Roger Mächler – Chief Financial Officer

Revenue

€1.6bn

Operating income

€383m

Capital expenditures

€166m

For the sixth consecutive year, the Octapharma Group can report a record-breaking result with sales of €1.6 billion, which represents an increase of €87 million or 5.8% compared with 2015. This outstanding performance is the result of enhanced collaboration and improved efficiencies across all functions and regions throughout the group. It would not have been possible without the focus, efforts and perseverance of all our employees and business partners.

Octapharma achieved sales growth of 18.8% in North America, 14% in Eastern Europe and 6% in our well-established markets of Western Europe. The main contributors of the growth were our immunoglobulin products octagam® and gammanorm®, and our factor VIII products octanate®, wilate® and Nuwiq®.

Gross profit in 2016 was €590 million, €8 million higher than in 2015. The 36.9% gross margin of net sales is slightly lower than last year due to our continued investment in the expansion of our plasma donation centres and production capacity. Our cost per litre of plasma is affected by both the industry-wide trend of increasing donor fees in the US and the opening of our new plasma donation centres. Expanding our fleet of centres is a high value investment for the future; however, time is required before the new centres are running to full capacity.

In 2016 Octapharma increased its investments in our future product portfolio and important markets; however, our total operating expenses decreased by €24 million to €207 million, due to an extraordinary income from a financial settlement. In addition to the €84 million investment in research and development (R&D), €166 million was spent on the extension of both our plasma collection and production divisions.

We achieved an unprecedented operating income of €383 million. Net cash from operating activities was €288 million or 18% of revenue. Trade receivables increased after a very strong fourth quarter and our net inventory rose due to welcomed greater volumes of collected plasma raw material.

Over the last five years Octapharma has experienced tremendous growth with a compound annual growth rate of 15%. Our development initiative, Program 2019, was launched in 2014 to double production capacity and significantly increase the overall efficiency of our manufacturing operations. We have been heavily investing in people, equipment and property to prepare for the increase in production capacity and volumes. While the technical infrastructure is largely in place, our focus is now on securing the necessary regulatory approvals to transform our investments into increased product availability for patients.

During a strategic workshop the Board focused on where we want the company to be by 2026. Our new strategic goals are: increase market penetration and expand into new geographies; expand the plasma and recombinant product portfolios and optimise R&D timelines; optimise production efficiency; increase plasma collection and fractionation capacity; proud and talented employees in a healthy organisation; and open and transparent communication. These pillars are at the forefront of planning and help to guide all the decision making and priorities of the Octapharma Group.

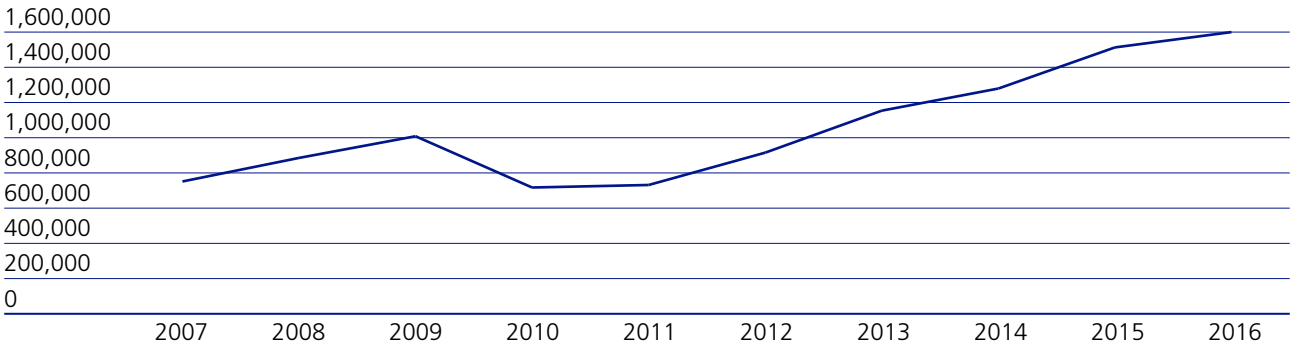
Our target for 2017 is sales growth of more than 10% and absolute profit results which are comparable to 2016. This year is expected to be the final transitional period before we finally start harvesting the real benefits of the profound investments made in plasma collection and production.

I am optimistic that Octapharma will continue to be in a strong position to deliver new health solutions advancing human life.

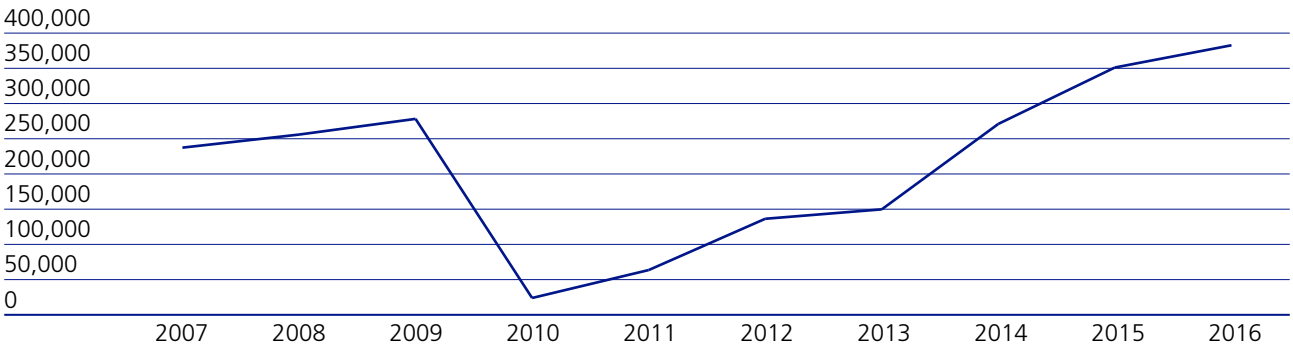
Roger Mächler
Chief Financial Officer

Key Figures of the Octapharma Group

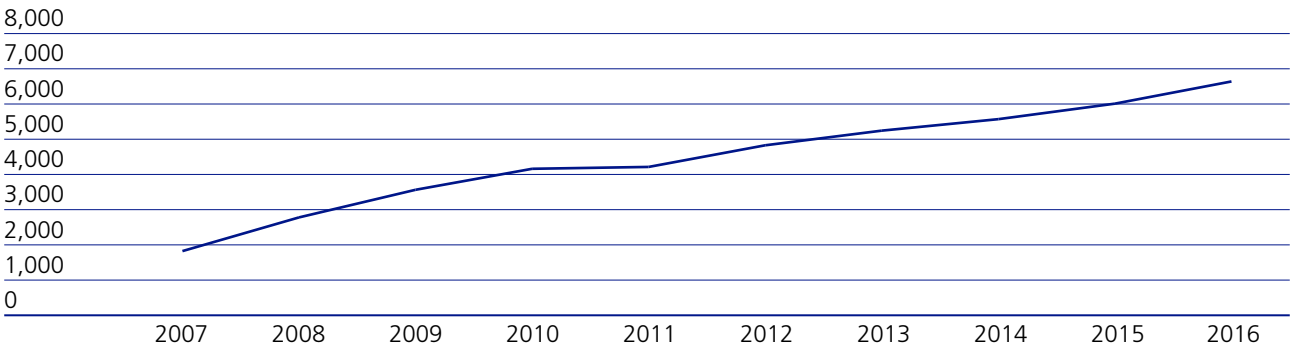
Revenue in 1,000 EUR



Operating income in 1,000 EUR



Average headcount



(Monetary figures are in 1,000 EUR)	**2016**	2015	2014	2013	2012
Operating income	**382,776**	351,239	271,192	149,924	136,778
Net profit of the year	**345,450**	330,267	236,136	124,398	135,755
Year-end headcount	**7,094**	6,213	5,683	5,514	4,939
Return on investment	**15.3%**	17.0%	14.2%	8.5%	10.0%
Profit from operations per employee	**58**	58	49	28	28
Cash ratio	**180%**	174%	122%	79%	19%
Days of sales in receivables	**137**	123	135	123	122
Days of purchases in inventory	**218**	227	249	274	379
Cash flow from operations	**287,966**	382,437	274,541	205,558	131,559
Expenditures to ensure future prosperity	**249,611**	242,383	168,265	111,236	97,637
Research and development	83,500	72,825	41,792	45,780	36,741
Capital expenditures and investments in activities	166,111	169,558	126,473	65,456	60,896

Financial Statements of the Octapharma Group

The following summary financial statements are derived from the consolidated financial statements of Octapharma Nordic AB, Stockholm and comprise the summary income statement for the period from January 1 to December 31, 2016, the summary balance sheet and the summary cash flow statement for the year then ended, aggregating non-material financial statement captions.

Consolidated Income Statement of the Octapharma Group

(All figures in 1,000 EUR)	**2016**	2015
Revenue	**1,600,057**	1,513,044
Cost of sales	-1,010,219	-930,656
Gross profit	**589,838**	582,388
Research and development	-83,500	-72,825
Selling and marketing	-94,659	-96,483
Regulatory affairs	-14,213	-13,724
General and administration	-51,525	-53,910
Other income	38,023	6,917
Other expenses	-1,188	-1,124
Total operating expenses	**-207,062**	-231,149
Operating income	**382,776**	351,239
Non-operating income and expenses	5,368	11,905
Profit before taxes	**388,144**	363,144
Income tax	-42,694	-32,877
Net profit of the year	**345,450**	330,267

Consolidated Statement of Financial Position of the Octapharma Group

(All figures in 1,000 EUR)	**2016**	2015
Assets		
Cash and cash equivalents	445,467	392,658
Trade receivables	601,850	510,795
Other receivables	27,240	9,882
Loans to related parties	139	77
Derivative financial instruments	403	607
Inventories	597,955	535,724
Other current assets	51,858	35,323
Total current assets	**1,724,912**	1,485,066
Financial investments	15,256	4,422
Deferred tax assets	77,872	72,535
Loans to related parties	821	867
Investments in associates	11,058	17,911
Property, plant and equipment	565,677	479,269
Intangible assets	14,729	35,362
Total non-current assets	**685,413**	610,366
Total assets	**2,410,325**	2,095,432

(All figures in 1,000 EUR)	**2016**	2015
Liabilities and equity		
Trade payables and other payables	96,698	87,619
Derivative financial instruments	3,333	0
Income tax payables	30,100	23,145
Accruals	90,493	88,345
Current provisions	26,688	27,167
Total current liabilities	**247,312**	226,276
Deferred income	2,593	2,652
Provisions	92,869	81,252
Deferred tax liabilities	25,846	22,180
Other non-current liabilities	215	245
Total non-current liabilities	**121,523**	106,329
Total liabilities	**368,835**	332,605
Share capital	100	100
Retained earnings	2,009,836	1,734,938
Currency translation adjustments	31,554	27,789
Total equity attributable to owners of the company	**2,041,490**	1,762,827
Total liabilities and equity	**2,410,325**	2,095,432

Consolidated Statement of Cash Flows of the Octapharma Group

(All figures in 1,000 EUR)	**2016**	2015
Net profit for the year	**345,450**	330,267
Depreciation of property, plant and equipment	77,759	61,539
Amortisation and Impairment of intangible assets	20,632	25,327
Change in fair value of non-current assets	9,724	-3,601
(Profit) loss on sale of property, plant and equipment	542	-80
Changes in long-term liabilities and provisions	8,476	19,259
Unrealised foreign exchange (gain) loss	1,810	-4,548
Cash flow before changes in working capital	**464,393**	428,163
(Increase) decrease of working capital	-176,427	-45,726
Net cash from operating activities	**287,966**	382,437
Acquisition of property, plant and equipment	-166,111	-114,885
Investment in IP rights and shares of associates	0	-80,000
Change of financial investments	93	-121
Proceeds from sales of property, plant and equipment	339	479
Net cash used in investing activities	**-165,679**	-194,527
Financing activities	-70,000	-70,000
Net cash used for financing activities	**-70,000**	-70,000
Net change in cash and cash equivalents	**52,287**	117,910
Cash and cash equivalents beginning of period	392,658	272,552
Effect of exchange fluctuation on cash held	522	2,196
Cash and cash equivalents end of period	**445,467**	392,658

Report of the Independent Auditor on the summary financial statements

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REPORT OF THE INDEPENDENT AUDITOR ON THE SUMMARY FINANCIAL STATEMENTS

Octapharma Nordic AB, Stockholm

Opinion

The summary financial statements on pages 72 to 76, which comprise the summary balance sheet as at December 31, 2016, the summary income statement and summary cash flow statement for the year then ended, and related notes, are derived from the audited financial statements of Octapharma Nordic AB, Stockholm, for the year ended December 31, 2016.

In our opinion, the accompanying summary financial statements are a fair summary of the audited financial statements, on the basis described on page 72 of the annual report 2016.

Summary Financial Statements

The summary financial statements do not contain all the disclosures required by International Financial Reporting Standards (IFRS). Reading the summary financial statements and the auditor`s report thereon, therefore, is not a substitute for reading the audited financial statements and the auditor`s report thereon.

The Audited Financial Statements and Our Report Thereon

We expressed an unmodified audit opinion on the audited financial statements in our report dated February 27, 2017.

Management`s Responsibility for the Summary Financial Statements

Management is responsible for the preparation of the summary financial statements on the basis described on page 72 of the annual report 2016.

Auditor's Responsibility

Our responsibility is to express an opinion on whether the summary financial statements are a fair summary of the audited financial statements based on our procedures, which were conducted in accordance with International Standard on Auditing (ISA) 810 (Revised), *Engagements to Report on Summary Financial Statements*.

KPMG AG

Orlando Lanfranchi
Zurich, 27 February 2017

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