Bloodline

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HFNZ

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THE H WORD

This month, I have exciting news: After many years I am delighted to advise that the Haemophilia Foundation now has a permanent home. A commercial property has been purchased in Alicetown, Wellington.

It has been a long time coming, and we are pleased that we now have a space to call our own. We have been planning this purchase since 2007, when HFNZ became a single financial entity for the purposes of registering as a charity. In that time earthquakes, pandemics, and more have challenged us. That we now have a home is testament to the hard work and forethought of consecutive boards and members.

I think that this is more than just a building. Rather, it is an investment in the future of the Foundation. We now have a central space, close to the seat of government, where we can meet, share, and socialise. We can again display our important artefacts, to help us remember what ties us together. We also have the security of a sound financial investment, an asset that will secure the Foundation into the future.

The building is currently tenanted, and we look forward to moving in in the New Year. You can read more about the space later in this issue.

It was pleasing to see the National Youth Committee holding a hui in Wellington to bring together some of our younger members. This event, for members aged 18 - 30, was the first for a while, and was the starting point for more to come. It's important that we support our youth members, as they are the future leaders of our Foundation. Thanks must go to Lauren and Hemi for their focus on putting youth at the front of our thinking.

With the scaling back of some of the protections put in place at the peak of the Covid 19 pandemic, we are all looking forward to more certainty around HFNZ events and workshops, like the Youth Hui. We have an Adult Wellness Weekend planned for late November, as well as our National Family Camp in April 2023. It is important that we are able to maintain connections across the membership, and these events are central to that.

In terms of fostering connection across the wider bleeding disorder community, we were pleased to welcome representatives of the Fiji Haemophilia Foundation to our last Board meeting. Aotearoa and Fiji are now partners in WFH's twinning programme. That means that the two groups are working together to support the growth and development of bleeding disorder supports and services in Fiji. This is important work, and we're looking forward to working with the Fiji Foundation.

Deon York

HFNZ President

From the CEO

BY SUE ELLIS

Sadly, this will be my last annual report as I am retiring at the end of November, my last working day attending the AGM on Sunday 27th November. After four years in the role of Chief Executive, I have learnt an enormous amount about bleeding disorders, the importance of being real and ensuring people are valued and listened to, about what the concept of family means and the ties that bind through the diagnosis of bleeding disorders.

I will always value my time with the Foundation, particularly the wonderful and supportive people I have met through attending events such as Family Camp, Youth Camp, Adult Weekend, Women's Weekend and regional events. It was also a great time to be here when we celebrated the 60th Anniversary of HFNZ.

Over the four years of my time, almost three of those years were taken up with the Covid-19 in our lives. This had a huge impact with events either cancelled or postponed and ensuring we stayed connected with each other, even if that wasn't face-to-face. It has been an interesting time, to say the least and it was with relief to hear the lifting of our restrictions to bring us almost back to normal.

In June after a postponement during lockdown, we eventually got together for a wonderful weekend in Dunedin for Women's Weekend. With 36 women in attendance, it was a clear sign how much the connections were important and needed. We enjoyed some entertaining but very informative presentations, particularly Dr Claire McLintock's keynote speech on Menstruation and Psychology, and Dr Richard Egan's workshop on Managing Life in Changing and Uncertain Times, as well as a great panel of clinicians led by Hematologist Catherine Neal who answered questions and clarified a number of concerns. Everyone enjoyed the outside visits around Dunedin and the trip to Carey's Bay for dinner.

This year, at long last after postponements, our Youth Leadership event was held in Wellington in early September, led by Lauren as the Youth Representative and assisted by Hemi. This was an opportunity to reconnect, to spend time just socialising and looking ahead for some leadership training.

It is exciting to be planning our next event, the Adult Weekend. This is being held 25th and 26th November in Auckland. We already have a really interesting programme drawn up and I'm sure everyone will enjoy being back together again. The AGM and Board meeting is also linked to this weekend.

In August we published the results of our research looking at how well the Foundation is meeting the needs of our older members, "Te Roopu Rangatira: Our holders of Knowledge". Undertaken by Sarah Elliott as the lead researcher, the findings were mixed with a number of participants noting the support they receive from the Foundation but there were concerns that we need to do more, especially helping our older members to navigate through the health system. The report

on this research can be accessed on the Foundation's website.

Keep an eye out for the Foundation's National Family Camp in April next year. This will be held at the Ngāruawāhia Christian Youth Camp. I will be sad to not be there to experience the great mahi that families will enjoy coming together but know they will be well looked after by the Outreach Workers and clinical team.

In 2017 HFNZ was contacted by a member requesting a subsidy for period products for women with bleeding disorders. This prompted HFNZ to take a closer look at what those needs were, how HFNZ women experience menstruation, the effects on them and on their whānau/families. A survey was undertaken to learn the extent of members' experiences with menstruation. The results clearly showed that people with bleeding disorders are inordinately affected by extreme symptoms and by very high costs associated with menstruation products.

While the issues on menstruation for people with bleeding disorders remain central, a project is currently underway that takes a broader approach for girls, women and gender diverse people who are affected by the symptoms of their bleeding disorders to better inform and increase awareness of the signs and symptoms of bleeding disorders to primary health practices and to schools . Look out for an email asking, "What do you want the GP and teachers to know about your bleeding disorder?"

After sixteen months in her role as our Southern Outreach Worker Rosie Maguire said goodbye for her overseas experience. Although it was sad to say auf vedersain we know that this experience will be a lasting memory for her. Laura-Lee Perawiti in Hamilton also took up the opportunity presented to her to move into the academic world to teach at the Waikato Te Wananga Aotearoa.

After a brief recruitment process we welcomed Tara Williams-Tuschling as our Southern Outreach Worker. Tara is a Registered Nurse and has quickly got into her role and understanding of all things bleeding disorders. Keep an eye

out for her as she travels around Te Waipounamu meeting members. By the time this report comes to you we will also have with us our new Outreach worker for Midland, Loren Silva. Loren comes to us with a background in Social Sciences recently working in peer support with people recovering from mental illness.

I am very pleased, after years of waiting, that we now have a home to call our own with the purchase of a national office. The new office is situated in Lower Hutt, Wellington. By the time you read this, the Foundation will be getting ready for the move into its home.

I want to take this opportunity as my last report to thank all the wonderful people who have supported me during my time with the Foundation. In particular, the staff both those past and current. I feel very confident the staff will continue to help support and care for members in their regions and across the country and members are in safe hands. I also want to thank the Executive and the Board for all their support, especially as we collectively navigated our way through the pandemic and lockdown.

Saying 'thank you' will never be enough to all those wonderful people who continue to send us generous donations. Even during lockdown and pandemic restrictions, people are thinking about other's needs. It does give me hope. Again, the Kiwifirst teams just keeps on doing what they do best and constantly reaching above targets. Thank you to Marty and Steve for all your wonderful support for me and your friendship. ***Ehara take toa, he takitahi, he toa takitini - My success should not be bestowed onto me alone, as it was not individual success but success as a collective.***

I am also grateful to the Haemophilia Treatment Centre teams – you know who you are! Your fantastic support of the Foundation and training given to new Outreach Workers have given them a greater understanding of all matters bleeding disorders and the confidence in their role to support and care for members.

Thank you also to the pharmaceutical industry who have continued to support us with grants allowing us to provide the important events to members. I have very much enjoyed meeting with all of you individually over coffee and chats.

As I sign off for the last time, I wish you all well but know the Foundation is in good hands and there are exciting times ahead. I wish the new Chief Executive all the best and know they will enjoy their role as much as I have.

Ngaro atu he tetekura, whakaete mai he tetekura – When one chief disappears, another is ready to appear – No one is indispensable.

Rorie Poff

BY RORIE POFF

On the 26th May 2022 a team of 30 athletes including myself travelled over to the Gold Cost for a tour in preparation for the Oceania's in Mackay. I left New Zealand and landed on the Gold Coast for the pre-competition camp. As you can imagine the weather on the Gold Coast was a lot warmer than Christchurch.

Day one was settling into the accommodation that I shared with three other athletes, which had a shared kitchen and a pool area for relaxing. This was also a good time to connect with older athletes. Then there was some light training prior to the Gold Coast Athletics Competition on the Saturday. At that competition, I achieved a personal best and enjoyed getting back into competing mode.

For the rest of the time on the Gold Coast, I alternated training in the gym with sessions on the track. I also managed to get to MovieWorld and a golf range in my downtime, and have a swim at Surfer's Paradise.

A priority for me was getting into a focused mindset and eating well, and of course keeping hydrated.

It was great to interact with the other athletes and train with the assistance of throws coaches. We had to be responsible for shopping for food and cooking our own meals.

We left to go to Mackay on 3 June and again settled into the accommodation and surroundings. The weather in Mackay was very hot and humid with one day being 27 degrees.

At this stage, the rest of the NZ team arrived and every one became even more focused.

I competed in the Mackay pre Oceania meeting on 4 June with throws of:

1. 9.49m
2. 9.37m
3. 8.78m

For the rest of the time in Mackay I went to the sports grounds to train, watch, and support other athletes. I also went to the gym to continue my training. Luckily, my coach was also in Mackay, and my father flew over to support me for the main event.

At the Oceania's, my event was on the very last day of the competition on the 11 June. I threw a personal best of 9.83cm with a 5th place result.

The whole experience was amazing, travelling internationally with the New Zealand team and the support of Athletics New Zealand.

I got into shotput originally because I was looking to pick up a new sport. I had been part of a programme to increase participation in running and movement for youth with disabilities. From this I then joined an athletics club were I did many different events and over time I found that I enjoyed shot put in particular, I realised that I

was good at that and that I could be competitive with shot put and then I got in touch with a coach whom I am still with, Hayden Hall.

I try not to let my bleeding disorder hold me back from what I am capable of and how I train, but at the end of the day I have always have to keep in mind that I need to be careful, and I do have a risk of having a serious bleed. I self-manage my treatments, and this is important to me because if I miss a treatment or am not careful enough this can affect my training and recovery.

I initially found out that I had been selected to represent NZ via email. When I found out I was proud of myself, and of what I had achieved. As soon as I found out, I rang my mum to tell her the great news. However, this information was confidential as I found out a couple hours before athletics New Zealand published that information to the public.

The whole experience was such a big learning opportunity, and I learnt a lot about myself that I didn't know. As this was my first time going away and representing New Zealand I tried to soak in as much as I could. I was very nervous as there were many other athletes and I didn't know what to expect.

To get in the zone when I'm competing, first of all I try to block out all of the outside noise and just try and stay focused on what I need to do and why I am here. When I compete, I like to sit by myself and think about my next throw, and how I can do better.

Going into the Oceania competition, I knew it was going to be tough. I was going into the competition as the youngest competitor; however, I was ranked third out of 12 competitors prior to the event, so I knew I had to prove myself. Getting to the track on the morning of my event, I went through all my warm up and preparation and then it was time to go into the call room. I was quite nervous going into the call room, as I didn't know what to expect. All the others competitors had done this before, and know what they were doing, so I sat down and got ready. After waiting to get called for the event, we all walked out to the track. At this time, I was getting really nervous, but I was ready to compete. When we finally got started, I could feel the nerves building up. Out of six throws, I only got one legal throw in on my second round, which was 9.83m, and a personal best for me. I finished the competition in fifth place. Although I did not achieve what I wanted to, I left that competition feeling like I had given every one of my throws 100% effort, and that I had accomplished something that I was proud of.

The goal has always been to go to the Paralympics for New Zealand, and I know that for that to happen I need to put in a lot of hard work next season. I really want to achieve as much as I can, and I hope to get the opportunity to represent New Zealand again.

Finally, I would like to thank HFNZ for your generous support in helping me to attend the Oceania Competition.

A new home for HFNZ

The Haemophilia Foundation of NZ is very pleased to announce that we are now the proud new owners of a commercial property in Alicetown, Lower Hutt.

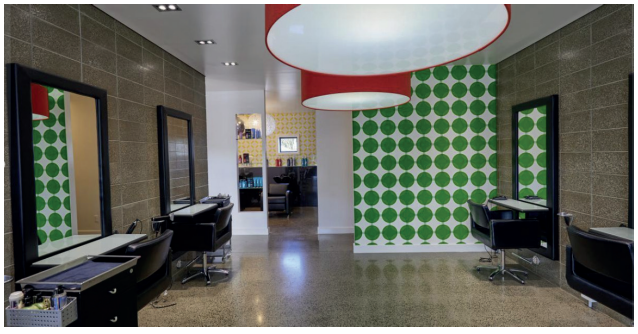
The property, at 44 Victoria St, is well suited to our needs. It is all ground level, is situated close to main transport routes, and has several off-street car parks so it is accessible to all. It has a variety of indoor spaces that are easily configurable to suit our needs. The building currently has two tenants: a hairdresser and a chiropractor. One is the previous owner, and will vacate early in 2023. The other will remain as an ongoing tenant. We expect to be able to begin the process of moving in around March 2023.

This is the culmination of a plan that started way back in 2007. At that time HFNZ were required to consolidate the regional bank accounts into one account in order to fulfil the requirements for registration as a charitable entity. It was agreed that the funds available at that time be earmarked for the purchase of a property for the benefit of the Foundation. Since then the HFNZ board have resolved to add to that fund by applying the proceeds of major bequests to it. Thanks to their foresight, we were this year in a position to make an offer on this property.

Decisions are yet to be made on exactly how we will use the building. Of course, all our important things will now have a home, and there will be space for staff to work as required. We will now be able to hold board and staff meetings in our own space, as well as offer the space to other organisations to meet in. Additionally, we now have a space close to the seat of government, which helps provide better access to decision makers.

However, this building is more than a place of work. It is also an investment in the future of our Foundation. With the potential for ongoing income from the tenantable space, and the steady appreciation of commercial property values, this asset helps assure the longevity of HFNZ.

Most of all though, we now have a home.



Te Roopu Rangatira: Our holders of knowledge

AGEING WITH BLEEDING DISORDERS

This year HFNZ undertook a research project, Te Roopu Rangatira: Our holders of knowledge, to determine how well HFNZ is meeting the needs of members aged 55 and over. Sarah Elliott, social worker and former HFNZ outreach worker, led the survey, overseen by the HFNZ CEO and supported by the Communications Manager.

The findings of Te Roopu Rangatira: Our holders of knowledge were informed by a written survey, a focus group, and four individual interviews. Forty-one people completed the written survey, and their responses guided the subsequent four-person focus group and four individual interviews. In total, 208 surveys were distributed to members in the 55 plus age group. Of the 41 responses, 21 were women and 20 men, 34 were Pākēha, four Māori, and three of other ethnicities.

The survey found that 48% of respondents think that HFNZ is effective in meeting their needs, while 29% believe that HFNZ is ineffective. Furthermore, 88% think that HFNZ could change or improve their services. Of the services HFNZ provide, 36% said that outreach support was the most valuable; 18% selected Bloodline, Pānui, and other information; 14% selected conferences and workshops; 14% selected socialising and social events; and 9% highlighted footwear vouchers.

Regarding information specific to their needs, respondents were most interested in new treatments, pain management, remaining active, exercise, and weight management.

The most common theme for specific services was more contact with their outreach workers. Concerns were expressed about staff turnover and the need for rapport building. Forty-five percent of respondents thought their outreach worker was supportive, while 20% felt they were unsupportive. The most common response (35%) was that they felt moderately supported.

Participants noted a lack of connection and most had not seen an outreach worker for many years, or may have a quick catch-up once a year that did not focus on getting into the details of their specific needs and issues. There was a lot of discussion about the recruitment of outreach workers and the types of people participants thought best suited to an outreach role, including those outreach workers from outside the bleeding disorder community who need to spend time upskilling especially related to the impact of bleeding disorders on older people. They suggested outreach workers need regular training/hui where they meet with a group of active parents and an older member to share their experiences and gain insight.

The focus group broadly focused on access to services and supports, outreach support, social supports, and HFNZ support. The key them that ran through this group was concern about their own physical health. This is particularly interesting given the sessions and questions were developed to focus on services and supports.

Most people found that the medical system could be tricky to navigate, including knowing which specialists to follow up with. There was a clear concern about medical professionals' lack of bleeding disorder knowledge. Participants felt they were sometimes lost in the hospital system, and found the medical system slow in meeting their needs. They found it hard to access the equipment they need and were often waiting very long periods. They discussed the possibility of HFNZ funding some of this equipment, which is essential for mobility and quality of life. There was significant feedback about whether outreach workers were able to help advocate and support them to get the equipment they need, and at hospital appointments, as well as having knowledge of what resources are available to members.

The importance of social connection with others with bleeding disorders was another key theme for everyone. The participants were very clear that face-to-face time together was essential and should be a main role for HFNZ and outreach workers. Camps, workshops, meetings, and social events should provide a space for discussions, support, and sharing. This was more important than the education sessions for many.

When talking about HFNZ specifically, participants felt that HFNZ was no longer visible, that they have "wound down" and they were not sure what HFNZ actually does, as they do not see a lot anymore. There were not many suggestions about what changes HFNZ may need to undergo to better support their older members, although did suggest HFNZ need fresh people on the Board with new ideas, passion, and enthusiasm.

Full report available at: https://www.haemophilia.org.nz/files/te-roopu-rangatira---our-holders-of-knowledge.pdf

The HFNZ outreach service

The outreach service exists to support and advocate for HFNZ members across Aotearoa. Every member has different needs, so the way each OR worker engages with members is flexible. Likewise, the region each OR worker covers is large, so they have to find ways to cover all corners. For those close to home base, a visit isn't too difficult. Sometimes, however, it means using other methods, like telephone, email, and video calls. The OR team also undertake regular trips around their regions, connecting with those further afield.

The HFNZ outreach service covers all of NZ, based on four specific regions: Northern, Midland, Central, and Southern. Northern covers the top of the motu, from Cape Reinga to the Bombay Hills. Then we move into Midland, which continues down as far as Taupo, before turning into the Central Region. Central continues to the bottom of the North Island. Everything south of that is Southern, including Wharekauri, the Chatham Islands.

Some members don't really want visitors, which we totally understand. The OR team are fully vaccinated, and are always happy wear a mask when meeting with you. If you'd prefer another way of meeting, just let them know.

HFNZ OR Workers have their own individual skills and strengths, and come from a variety of backgrounds. Darian, the Northern OR worker has a counselling background, while Loren, our new OR in Midland has a psychology qualification and experience in peer support. Lynne, our longstanding Central OR worker comes from teaching, and has a vast store of bleeding disorder knowledge. Tara, our new recruit for the Southern region, is a registered nurse, who comes to us via the NZ Blood Service. You can read more about the HFNZ staff team here: https://www.haemophilia.org.nz/about-us/about-the-foundation/meet-the-team

Because every member has different needs, we have a variety of services designed to support members at different life stages.

Good health is a key factor in managing a bleeding disorder. With this in mind, HFNZ can help support members to attend exercise programmes, like swimming or the gym.

We also offer supportive footwear grants, because we know that a decent pair of shoes is one of the easiest ways to protect against joint damage. There are criteria associated with these grants, so talk to your OR worker to find out more.

With prices going up across the board, sometimes you just need a wee boost to help you keep your head above water. The Outreach team can help by facilitating a needs grant. These small grants are available to HFNZ members undergoing hardship. Contact your OR worker to find out more.

HFNZ never wants money to be a barrier to member participation. If you want to attend an HFNZ event, but the finance just isn't there, reach out to your OR worker. Our first priority is always to get you there, and we're usually happy to organise a payment plan, or to look at other solutions.

The outreach service are also there to support you in non-financial ways. One of the key areas is advocacy and support. You don't have to wait until something goes wrong to let your school or employer know how your bleeding disorder affects you. Your OR worker can talk to the staff at school, or support you to talk to your employer and colleagues, about just what having a bleeding disorder means. This is a key service for those who are newly diagnosed, or who have not had to deal with discussions like this before.

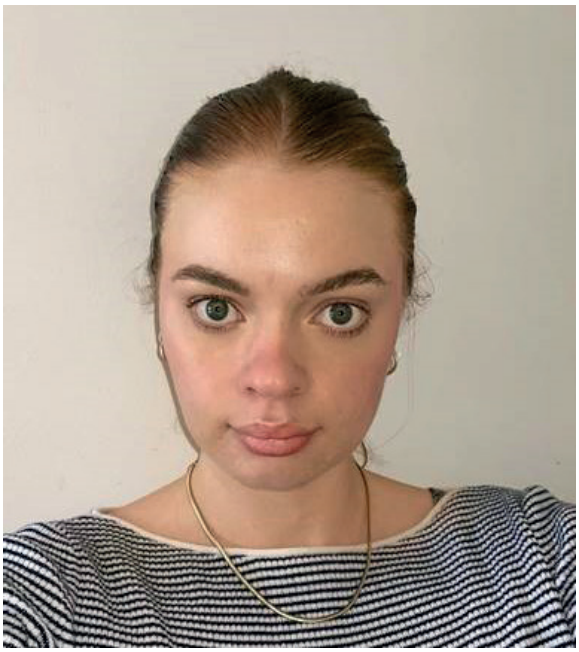
The outreach service also offers support when you have appointments to attend, like your GP, your hospital, or WINZ. They can offer a friendly presence who is willing and able to help you navigate the health system and advocate for you when required.

Perhaps most importantly, the outreach service can help connect members to others with similar experiences. Living with a bleeding disorder can often feel like a lonely vigil. Bleeding disorders are rare, so the opportunity to share your experiences with someone who has had the same experiences does not happen often. The outreach service offers regular events and other opportunities to bring members together.

It's important to remember that the outreach team can offer a listening ear when things are tough. Your OR worker is happy to be approached with any issue at all. It's always better to ask for support, than to suffer in silence. If it's not something they can help with directly, then they will be able to point you in the right direction.

Outreach is not a crisis service, but they can support you to access the service you may need. If you want to speak to an OR worker you can contact them by calling 0508 FACTOR (322 867). Individual OR contact details are available on our website: https://www.haemophilia.org.nz/contact-us/

DARIAN SMITH
NORTHERN



LOREN SILVA
MIDLAND

LYNNE CAMPBELL
CENTRAL

TARA WILLIAMS-TUSCHLING
SOUTHERN

Yth Hui

On 2-4 September 16 of our youth members made the trip to Wellington for a weekend of reconnection, teamwork and some friendly competition. The weekend was facilitated by Lauren Phillips and supported by Hemi Waretini and Darian Smith, HFNZ's Northern Outreach Worker.

The weekend kicked off at Escape Rooms Wellington where the group was split into three teams and locked in their own unique adventure to discover clues, solve puzzles, and accomplish tasks as a team in order to escape! This tested our ability to work together, our communication skills and sometimes our patience. It was great to see everyone get stuck in, share ideas freely and take charge at different points during the game meaning that we all escaped with just minutes to go!

After a short but cold break out in the Wellington weather we were on to our next activity – axe throwing! We had a comprehensive safety briefing (don't touch the sharp part of the axe and don't walk in front of someone throwing an axe) and got straight into some training. Despite looking like a sport for lumberjacks – there was a decent amount of skill required rather than just brute force. Once we had warmed up, we were split into pairs to compete against each other. Everyone managed to land at least one axe in the board – which is much harder than it looks. Next we had a team vs team event of "speed throwing" where each team had one minute to get as many points as they could by throwing as many axes in the board as possible (don't worry it was absolutely safe). The supreme winner on the day though was Tarquin but honourable mentions also go to Jayden, Cole, John, R-Leeo and Shan (who took out best dressed).

Brian Ramsey (BJ) the Wellington Haemophilia nurse popped in on the weekend to talk to us about advances in treatment including Hemlibra (emicizumab). There were some interesting questions that came up about how treatment is funded overseas – particularly in the USA, as well as things to consider while travelling with haemophilia. We also touched on some of the overseas opportunities for people with bleeding disorders including SURO, AFFIRM and involvement with twinning projects.

Saturday night we descended on Big Thumb restaurant for dinner with our President Deon York. After dinner there was plenty of discussion about what youth wanted for the future of the foundation and also a lot of reminiscing about the activities they did with HFNZ as a child which made the more "mature" youth members feel incredibly old. It was awesome to see that people have such strong memories of the role that the Foundation has played in their lives. These stories reinforced the importance of ensuring we continue to build on those events.

The chance to be in the same room and meet in a social setting created the opportunity for some really good discussions about the experiences and needs of youth since the pandemic began and into the future. One of the key topics of discussion that came up over the weekend was the impact that covid has had on our youth and youth generally. Many have missed out on the typical experiences of young people like attending university or polytech in person, travelling, the social aspects of starting your first job or simply being able to do normal day to day things without restrictions. We're glad that this weekend managed to bring some normality back to the way we do things at HFNZ and reinvigorated or youth members' connection with HFNZ.


#sweetaxethrow

Dental treatment for individuals with inherited bleeding disorders

A CDHB PERSPECTIVE

Data extrapolated from the Canterbury District Health Board haemostasis service shows the total number of patients referred in 2021 for dental treatment (fig 1). Patients with vWD account for almost 70% of all the referrals, corresponding to its higher frequency in the population. The audit also found that at CDHB, 60% of the referrals were from the hospital dental service and 40% from a combination or private dentists, GPs and self-referrals.

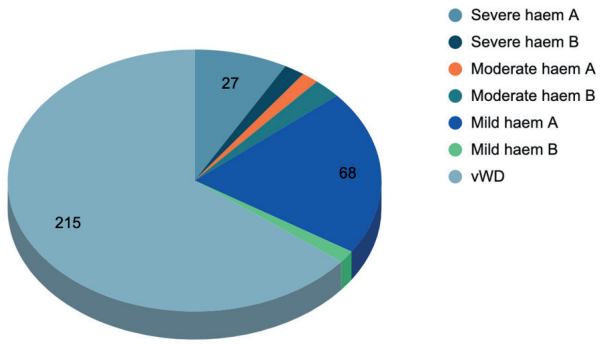


Fig 1 - Bleeding disorder distribution in CDHB haemostasis patients refered for dental treatment

Those living with inherited bleeding disorders can experience the same oral disease as those without. However, prolonged bleeding and the reluctance of general dentists to treat such individuals can complicate their dental treatment. Thus, education and prevention with good oral hygiene is imperative and should be stressed to this group.

Patients with bleeding disorders have:

- Fear of bleeding during brushing/ flossing
- Fear of prolonged bleeding following dental treatment
- Lack of confidence in the dentist due to the perceived limited understanding of their condition

These can lead to an increased waiting time before accessing dental care in hospital, rather than locally, as some dentists are reluctant to provide even simple dental care.

The literature available regarding oral health and inherited bleeding disorders is conflicting and, due to the rare nature of the conditions, the studies have limitations.

The gold standard of dental care for these patients involve a multidisciplinary approach between the dentist, haematologist, and the GP, with the patient at the centre of the process to empower them to become experts in their own care. A shared understanding of what is required for the patient is what we should be striving on a national basis.

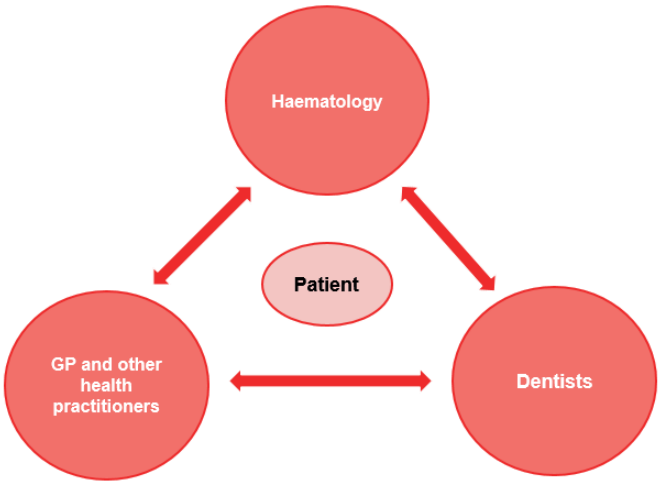


Fig 2 - A multidisciplinary approach is the gold standard

However, patients are often scared of dentists because of their condition, dentist are scared of having "bleeders" on their hands, and haematology teams do not always have a full understanding of the treatment dentists provide. As a result, dental care in this group is often neglected, with a high level of untreated dental disease causing pain and adds to the complexity when invasive interventions such as extractions are required down the track.

In NZ there are six inherited bleeding order treatment centres: Auckland, Hamilton, Palmerston North, Wellington, Christchurch, and Dunedin. After contacting the different haemophilia treatment centres, it appears that most regions have a system whereby the dentist emails the haemostasis service with information about the patient and the dental treatment they require.

In 2012, the dental department and haematology team at CDHB came together to create a haemostasis service request form for patients with inherited bleeding disorders. It is a relatively simple form with a series of tick boxes, which the dentist completes. They then email the haemostasis nurse to access the appropriate support. The form provides the haemostasis team with specific information regarding the invasiveness of the planned dental procedure.

However, it is a standardised form, and does not take into account the severity of the bleeding disorder. Nor does it provide dentists with a quick, simple insight into the pre, peri, and post-operative management of these patients, which can often make it difficult to plan treatment.

We would like to improve the experience for all parties involved. This includes:

- Giving patients the confidence to seek dental treatment without complications of bleeding

- Giving dentists the confidence to treat patients with the appropriate haemostatic cover required
- Having a clear pathway for management or seeking advice if prolonged bleeding occurs.

I believe we need resources that are easily available that help dentists around the country deliver care for patients locally, and increase the accessibility of care, as the burden of travelling to the nearest hospital dental service can be an obstacle to seeking timely treatment.

For patients, I propose a dental passport based on the information in the WFH treatment and care guidelines. This traffic light system simplifies and illustrates the advice for patients and dentists on which dental treatment is suitable with or without haemostasis support. This is simplified for patient understanding, but can be utilised as a useful education tool to aide and empower patients to seek dental treatment with more confidence.

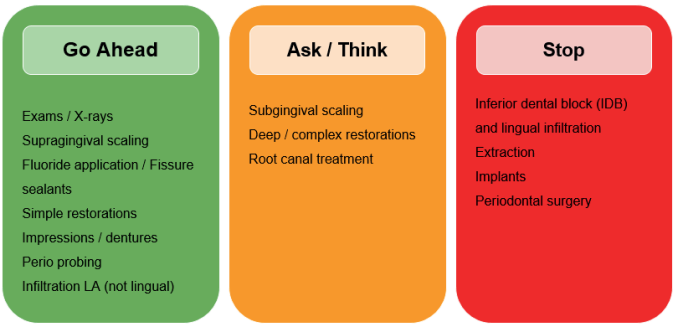


Fig 3 - Patient dental passport

For dentists and haematologists I propose a risk-based management tool.

This resource is based on the retrospective audit published by Dr Rasartanam and her team in the journal of the WFH in 2017. This tool is similar to the traffic light system for patients, but has greater depth. It provides a simple checklist to help determine the appropriate haemostatic cover for the required level of treatment. Risk groups are classified as mild or moderate/severe inherited bleeding disorders. Risk-based treatment facilitates the identification of high-risk patients for follow up, prevents unnecessary over-treatment in low risk patients, and appropriately utilises the available resources.

For individuals with mild bleeding disorders, a 5-7 day course of TXA mouthwash and/or tablets can be used to effectively control haemorrhage for a wide range of procedures. This includes periodontal probing, sub-gingival scale and polish, supra-gingival restorations, and root canal treatment, thus providing opportunity for relief of pain with pulpectomy.

Treatments		Mild bleeding disorder (Haemophilia A&B / Type I vWD)
Non-invasive	Periodontal probing	No routine intervention is required If there is bleeding, 5% TXA MW 10ml, QDS for 3-4 days or TXA tablets 1g TDS (5-7 days)
	Supragingival scale & polish	
	Impressions	
	Root canal treatment	
Minimally invasive	Restorations requiring rubber dam clamp / matrix band +/- infiltration LA*	TXA tablets 1g 2hrs **pre-op**, continue TDS (5-7 days) Or **Post-op:** 5% TXA MW 10ml, QDS (5-7 days)
	Non-surgical periodontal debridement +/- infiltration LA*	
Moderately invasive	Crown and bridge preparations (subgingival)	**Pre-op:** raise factor levels with factor concentrate or DDAVP > 30% **For mucosal procedures, post-op** 5 % TXA MW 10ml, QDS (5-7 days) or TXA tablets 1g TDS (5-7 days)
	Procedure requiring inferior alveolar nerve block &/ or lingual infiltration	
Highly invasive	Dental extraction	**Pre-op:** Raise factor levels with factor concentrate or DDAVP **Peri-op:** Minimise trauma to mucosa. Place oxidized cellulose pack (e.g. Surgicel) in extraction socket. Suture all extraction sockets **Post-op** 5% TXA MW 10ml, QDS (5-7 days) and TXA tablets 1g TDS (5-7 days)
	Periodontal surgery	

Fig 4 - Mild BD vmanagement tool

TXA used topically as a mouthwash or orally as a tablet can inhibit the breakdown of the fibrin in the blood clot for hours, increasing the stability of the clot. TXA is useful in treating superficial soft tissue and mucosal bleeds, which we commonly deal with as dentists. With the mouthwash, in order to benefit from systemic effects in patients with inherited bleeding disorders, a “rinse and swallow” technique is advocated.

Patients of all severities requiring a lingual or inferior nerve block are considered a moderate risk and there is consensus on the need for prophylactic cover with factor concentrates or DDAVP to prevent bleeding, which could compromise the airway. However, often infiltration anaesthesia and intra-ligamentary injections can be used to achieve sufficient anaesthesia of lower posterior teeth.

Treatments		Moderate/ Severe bleeding disorder (Haemophilia A&B / Type II & III vWD)
Non-invasive	Periodontal probing	TXA tablets 1g 2hrs **pre-op**, continue TDS (5-7 days) Or **Post-op**: 5% TXA MW 10ml, QDS (5-7 days)
	Supragingival scale & polish	
	Impressions	
	Root canal treatment	
Minimally invasive	Restorations requiring rubber dam clamp / matrix band +/- infiltration LA*	**Pre-op:** raise factor levels with factor concentrate or DDAVP > 30% **For mucosal procedures, post-op** 5 % TXA MW 10ml, QDS (5-7 days) or TXA tablets 1g TDS (5-7 days)
	Non-surgical periodontal debridement +/- infiltration LA*	
Moderately invasive	Crown and bridge preparations (subgingival)	**Pre-op:** raise factor levels with factor concentrate or DDAVP > 30% **For mucosal procedures, post-op** 5 % TXA MW 10ml, QDS (5-7 days) or TXA tablets 1g TDS (5-7 days)
	Procedure requiring inferior alveolar nerve block &/ or lingual infiltration	
Highly invasive	Dental extraction	**Pre-op:** Raise factor levels with factor concentrate or DDAVP **Peri-op:** Minimise trauma to mucosa. Place oxidized cellulose pack (e.g. Surgicel) in extraction socket. Suture all extraction sockets **Post-op** 5% TXA MW 10ml, QDS (5-7 days) and TXA tablets 1g TDS (5-7 days) Patient may require a second dose of factor concentrate.
	Periodontal surgery	

Fig 5 - Moderate to severe BD management tool

Extractions and periodontal surgery are considered highly invasive and require pre-operative cover with factor or DDAVP in all risk groups.

For surgical procedures, this tool also provides advice regarding peri and post op management, including providing patients with suitable analgesia options which include: paracetamol, COX-2 inhibitors such as celecoxib or tramadol. It is important to stress to patients that aspirin and other NSAIDs should be avoided as they can induce bleeding. Suitable analgesia include paracetamol, COX-2 inhibitors (e.g. Celecoxib), or tramadol.

Through this tool, unnecessary haemostatic cover and over-prescription of factor can be avoided. The study found that mild haemophilia/ vWD patients were often over-treated with factor concentrates or DDAVP to minimise the risk of potential bleeding, as the invasiveness of the dental procedure was not always obvious to the haematology team.

So, why don't we just provide factor treatment for all patients with bleeding disorders?

Factor concentrates are very expensive. Medsafe suggests that it can cost around $2000 for a 70kg patient for pre-op cover prior to dental treatment.

There is also a risk of developing inhibitors. Inhibitors are produced because the body sees factor concentrates as a foreign body, and activates an immune response. Approximately 20-30% of people with severe haemophilia A develop inhibitors compared to <6% for patients with haemophilia B. Patients with inhibitors require alternative treatment regimens to control bleeding, such as FEIBA, Emicizumab, or immune tolerance which adds extra cost and complexity to the haemostatic management. Therefore, minimising exposure to factor concentrates is ideal.

It can also be an unnecessary burden on patients to travel to the nearest HTC to receive factor for routine dental care. Especially if it is considered over-treatment and therefore not required. There is now a lot of research available to validate that low-factor protocols are safe for a range of dental treatment.

In conclusion, a multi-disciplinary approach with good communication is the key to effective, appropriate, dental care. Simple resources for patients, dentists, and haematologists will be helpful for improving confidence and for shared understanding. Low-factor, risk-based protocols are safe and simplify dental treatment. These protocols help deliver care for patients as locally as possible, thereby increasing accessibility.

Women's Weekend 2022

BY LAURA-LEE PERAWITI AND LYNNE CAMPBELL

In recent years, there has been increased recognition of the unique issues faced by women with inherited bleeding disorders.

We held this two-day event for Women with inherited bleeding disorders aged 18 years and upwards in Dunedin from 10 to 12 June 2022. This event had been postponed from November 2021 because of Covid disruptions. It had been over three years since our last Women's Workshop.

The main aims of the weekend were to provide information and education, to empower participants to understand and work through the issues associated with their condition, and to develop a sense of community within the group. Karakia, mihimihi, and waiata was incorporated throughout the weekend.

Participants arrived late Friday afternoon and many enjoyed getting to know each other for the first time, while others enjoyed re-connecting. The programme went through to 1pm on Sunday.

While education was the primary focus of the programme, recreational activities and time for bonding was included in the programme, and appreciated.

After dinner on Friday night Kahurangi Carter delivered a thought provoking presentation on the importance of "Giving back to HFNZ from a Maori Women's Perspective".

Saturday's guest speakers were amazing and focused their korero around Māori practice models and how they use these in their clinical settings of mahi. The workshops and presentations they did were engaging for us all, fun and educational.

Dr Claire McLintock was the keynote speaker and her and her presentation "Menstruation and Psychology" was outstanding.

Dr Richard Egan's Workshop "Managing life in uncertain and changing times" was also very well received and highly pertinent given we are all living with Covid and unpredictability in our daily lives.

This year we were extremely fortunate to have a medical panel of Haematologist Catherine Neal, Physiotherapist Lee Townsend, and Clinical Nurse Specialists Maureen Campbell and Kathy Fawcett to offer practical and immediate medical advice in response to participants' wide ranging medical questions.

The panel were able to offer support and answer most queries that the members had. This was invaluable to have over the weekend. It was good to have Southern and Midland panel members there, to talk about the way each region is practicing.

The sharing of members' lived experience was one of the highlights of the weekend. This sharing space encouraged members to resonate support one another, and contribute to the kōrero. For members new to HFNZ, this weekend gave them a good knowledge base and some understanding of what HFNZ is about. For the members that have been with HFNZ for some time, this was an opportunity to re-connect and offer support to the new members and others. Respectful relationships were established for the first time that will be maintained throughout life.

Around the branches

2022 has continued to be a quiet time for the HFNZ regional branches. However, with the government protections now easing, more and more events and activities are being planned.

In the Northern region members have been invited to attend a community dinner on 16 October. This is the first event in the Northern region since the rock climbing in April. This is a great opportunity for members in the Northern region to reconnect, and start planning further ahead. The branch is also looking at getting something going for Xmas, and perhaps another event early in the new year. Watch this space...

The Central branch has recently held their biennial camp at El Rancho in Waikanae. This was another fantastic camp, with nearly 40 people in attendance. There were a number of activities enjoyed by all, despite the terrible weather, which included a family quiz, a junior talent quest, and eel feeding at Ngā Manu. Of particular note was the session by Martin Sloman QSM, who worked with the adults to help us reconnect and offered some tips to help us support each other.

Since the last report, the Southern crew have welcomed a new outreach worker, Tara Williams-Tuschling. Tara started on 08 August, and has quickly settled in to her role. Tara is a registered nurse, and comes to us by way of the NZ Blood Service. Her first order of business was to organise a community dinner. This was well attended and a great time was had by all. Tara is also planning an outreach visit to the lower South Island before the end of the year. You can connect with Tara by emailing tara@haemophilia.org.nz or by calling/texting 021 656 804.

Things have remained very quiet in the Midland region as far as events go. However, the branch is very pleased to welcome their new Midland outreach worker Loren Silva, who started on 04 October. Loren comes from a background in peer support, and has strength in event planning and management. We're really looking forward her connecting with our Midland whānau, and contributing her skills to the OR team. You can contact Loren by emailing loren@haemophilia.org.nz or by calling/texting 021 762 121.

The National Youth Committee recently held a Youth Hui in Wellington. This was an important first step in planning for what's coming up in the youth space. The focus of this event was reconnection. To that end, the group enjoyed the challenges of an escape room, and made sure to stand well back as they tried axe throwing! There were several young people keen to be more involved, so watch this space for upcoming youth events.

Managing Bleeding Disorders in Pregnancy Requires Early Diagnosis, Multidisciplinary Care

BY ROSE MCNULTY

A recent review details strategies for mitigating the risks faced by pregnant patients with hemophilia or von Willebrand disease and their children.

Pregnant patients with inherited bleeding disorders face an elevated risk of life-threatening bleeding during pregnancy, delivery, and the postpartum period, making the identification and management of these disorders crucial to the mother and newborn's health. A recent review details current knowledge on mitigating the risk for carrying mothers with hemophilia or von Willebrand disease (VWD) and their children.

Although healthy women experience changes to the hemostatic system throughout pregnancy, childbirth, and the postpartum period that support coagulation to minimize bleeding, these changes might not fully protect patients with hemophilia or VWD. Understanding the inheritance patterns of bleeding disorders and being aware of normal levels of procoagulant and anticoagulant factors in newborns is another key aspect of management.

Hemophilia is characterized by low levels of coagulant factors VIII or IX, and factor VIII in particular increases throughout pregnancy. Although the increase is normally sufficient in healthy women, the increase is inconsistent between women with hemophilia and may not be enough to prevent postpartum bleeding. Treatment by a multidisciplinary team at a care center affiliated with a hemophilia treatment center (HTC) is the ideal scenario for this patient group to reduce the risk of complications. Contextual information about the mother's family and prepregnancy counseling on the potential for genetic transmission would ideally be in place at the HTC.

To assure sufficient levels of coagulant factors are present at delivery, factor levels should be checked early in pregnancy and at least at 28 to 34 weeks of pregnancy. Desmopressin (DDAVP) or factor replacement therapy is recommended for patients whose factor levels are lower than 50% by week 34 of pregnancy, although factor replacement is the first choice if needed due to the potential risk of neonatal or maternal hyponatremia with DDAVP. The factor level target should be 100% to 150%.

Determining the gender of the fetus is also important, as males carry a 50% risk of inheriting the disease and being at risk of neonatal bleeding while females have a 50% chance of being carriers with mildly low factor levels and little risk of neonatal bleeding. Chorionic villus sampling (CVS) or amniocentesis to evaluate fetal DNA is suggested for mothers of male fetuses. At birth, intracranial hemorrhage is the greatest concern for a newborn with hemophilia.

VWD is a more heterogeneous condition than hemophilia, although some management aspects are similar. During pregnancy, von Willebrand factor (VWF) levels increase to mitigate bleeding at delivery, but there is significant variation in VWF levels in expectant mothers with VWD. Those with type 1 VWD tend to show bleeding profile improvement throughout pregnancy as factor levels increase. Those with type 2 VWD show an increase in defective endogenous VWF, but not in VW activity. In women with type 3 VWD, the most severe form, both VWF and factor VIII typically remain low during pregnancy. Factor replacement therapy can help compensate for the lack of natural factor level increases.

As in hemophilia, target factor levels should be a minimum of 50%, targeting 100% to 150% at delivery. Factor replacement therapy with VWF containing plasma-derived factor VIII concentrate has been the most used intervention, although recombinant VWF may be more effective, the study authors note. To manage the risk of postpartum hemorrhage, prophylaxis with antifibrinolytics is recommended, and postpartum tranexamic acid is recommended when the patient's bleeding score is high or there is a history of postpartum hemorrhage. As with hemophilia, DDAVP is another treatment option but carries concerns of maternal hyponatremia.

With hemophilia and VWD, the safety of neuraxial anesthesia has been called into question. Although it is still debated, experts agree that it should not be administered when factor activity is below 50%. In newborns, the greatest concern regarding bleeding complications is for those with type 2 or 3 VWD.

Overall, the review emphasizes the importance of early and accurate diagnosis of bleeding disorders in pregnant women and the fetuses they carry. Additionally, appropriate treatment for insufficient factor levels is crucial to uneventful pregnancy and birth. Treatment by a multidisciplinary care team and ideally involving an HTC are both key to improving the likelihood of a safe delivery for mothers and newborns.

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Janbain M, Kouides P. Managing pregnant women with hemophilia and von Willebrand disease: How do we provide optimum care and prevent complications? Int J Womens Health. 2022;14:1307-1313. doi:10.2147/IJWH.S273043

Source: https://www.ajmc.com/view/managing-bleeding-disorders-in-pregnancy-requires-early-diagnosis-multidisciplinary-care

Phase 3 Trial of SB-525, Gene Therapy for Hem A, Again Enrolling

AFFINE study resuming after changes made to protect against blood clots

BY MARISA WEXLER

Men with moderate-to-severe hemophilia A are again being enrolled in the Phase 3 AFFINE trial, which is testing the safety and effectiveness of SB-525 (giroctocogene fitelparvovec), an experimental gene therapy being developed by Pfizer and Sangamo Therapeutics.

Pfizer, the study's sponsor, had placed a voluntary pause on enrollment after some treated patients developed unusually high levels of clotting proteins. The U.S. Food and Drug Administration (FDA) then placed a hold on the trial.

The FDA lifted its hold earlier this year after reviewing trial data, and Pfizer adjusted the study's protocol to manage high clotting factor levels.

Now, Pfizer and Sangamo have also ended their voluntarily pause in dosing, announcing in a press release that enrollment is resuming this month, with dosing expecting to begin again in October. Results from the trial are expected in the first half of 2024, according to the companies.

Hemophilia A gene therapy aims to deliver healthy gene to liver cells

The AFFINE trial (NCT04370054) is expected to enroll 63 men, ages 18–64, with moderate to severe hemophilia A — meaning the activity of factor VIII (FVIII), the clotting protein that is dysfunctional in hemophilia A, is 1% or lower compared to what would be expected in someone without hemophilia.

Eligible patients are those who took part in a lead-in study of factor FVIII prophylaxis (NCT03587116) and are being recruited at sites that include the U.S., Canada, Australia, Brazil, Europe, and Japan. All trial sites are expected to be active by year's end, Pfizer and Sangamo stated.

Gene therapy trial participants will each receive a single dose of SB-525, delivered via infusion into the bloodstream, and then be followed for up to five years to assess its safety and efficacy.

The study's main goal is to assess the effect of treatment on annual bleeding rates after 15 months. Other assessed outcomes include FVIII activity, the use of replacement therapies, and patient-reported measures of life quality.

SB-525 is designed to deliver a healthy copy of the gene that encodes FVIII to liver cells, allowing the body to make a working version of the clotting protein. The therapy has been granted fast track, orphan drug, and regenerative medicine advanced therapy designations by the FDA.

Pfizer implemented the pause in enrollment because some treated patients saw their FVIII levels rise to above 150% of what is typical, which can increase the risk of blood clots.

The company had previously disclosed that one AFFINE trial patient developed deep vein thrombosis in the leg, a condition caused by blood clots that can be life-threatening. Upon review, the man was found to have a prior history of clots, which is a known risk factor for future clotting problems, and he should not have been included in the trial.

Source: https://hemophilianewstoday.com/news/phase-3-trial-sb-525-gene-therapy-hemophilia-a-resumes/

Report Suggests Valoctocogene Roxaparvovec Could Save Hemophilia A Patients Millions Over Lifetime

BY ERIN HUNTER

After 4 years, the 1-time cost of valoctocogene roxaparvovec appeared to be more cost-effective than the annual cost of emicizumab prophylaxis for hemophilia A, according to a new Draft Evidence Report.

The Institute for Clinical and Economic Review (ICER) released a Draft Evidence Report with updated information on the clinical effectiveness and value of valoctocogene roxaparvovec (Roctavian; BioMarin) for hemophilia A.

According to findings from the Draft Evidence Report, valoctocogene roxaparvovec could save a hemophilia A patient more than $4 million throughout their lifetime, while also improving their quality of life.

"BioMarin is pleased that ICER recognizes the potentially transformative impact of [valoctocogene roxaparvovec] as possibly the first gene therapy treatment for severe hemophilia A, and potential to not only deliver profound patient benefit, but also potential long-term health care savings," said Jeff Ajer, executive vice president, chief commercial officer at BioMarin, in a press release.

The Draft Evidence Report compared the 1-time cost of valoctocogene roxaparvovec to the annual cost of emicizumab prophylaxis. Total costs for valoctocogene roxaparvovec include treatment, treatment-related adverse events, treatment for bleeding, arthropathy, surgery, and costs not related to drugs.

Valoctocogene roxaparvovec had an estimated 1-time cost of $2.5 million, compared to a $640,000 yearly cost for emicizumab prophylaxis. ICER found that valoctocogene roxaparvovec saved costs and predict that it will increase quality-adjusted life years.

A single 6e13 vg/kg dose of valoctocogene roxaparvovec was observed to be well tolerated. The most common associated adverse effects (AEs) affected the liver.

Among participants, 80% had increased levels of alanine aminotransferase. Other AEs include elevated aspartate aminotransferase levels (67%), nausea (37%), headache (35%), and fatigue (30%).

Patients with hemophilia A, an X-linked genetic disorder, have blood that does not clot normally because their factor VIII protein does not function properly, which when functioning, will cause blood to clot. The result can be life-threatening blood loss from even minor injuries.

Factor VIII protein levels are less than 1% among patients with the most severe form of hemophilia Am which accounts for nearly 50% of all hemophilia A cases. One of the most common symptoms is spontaneous bleeding into the muscles and joints.

Traditional treatment for hemophilia A includes taking an antibody that mimics the missing protein 1 to 4 times per month. Another common treatment option would be to receive intravenous factor VIII infusions 2 to 3 times per week—though neither work perfectly. Many patients report breakthrough bleeds that can lead to joint damage and lower quality of life.

BioMarin announced plans to offer an outcomes-based warranty for valoctocogene roxaparvovec. This would allow patients to have 4 years of risk sharing.

REFERENCE

BioMarin Pharmaceutical Inc., BioMarin's Gene Therapy for Adults with Severe Hemophilia A, ROCTAVIAN™ (valoctocogene roxaparvovec), Assessed to Provide Substantial Cost Savings Per Patient in a Preliminary Independent Report. BioMarin website. September 15, 2022. Accessed on September 19, 2022. https://investors.biomarin.com/2022-09-15-BioMarins-Gene-Therapy-for-Adults-with-Severe-Hemophilia-A,-ROCTAVIAN-TM-valoctocogene-roxaparvovec-,-Assessed-to-Provide-Substantial-Cost-Savings-Per-Patient-in-a-Preliminary-Independent-Report

Source: https://www.pharmacytimes.com/view/report-suggests-valoctocogene-roxaparvovec-could-save-hemophilia-a-patients-millions-over-lifetime

Youth Camp 2021

THE YEAR AHEAD

25-27 November, 2022

- Adult Weekend
  Novotel Greenlane, Auckland

27 November, 2023

- HFNZ AGM
  Novotel Greenlane, Auckland

11 – 14 April, 2023

- National Family Camp
  Ngāruawāhia Christian Camp, Ngāruawāhia.

Visit www.haemophilia.org.nz for more information on bleeding disorders, HFNZ News, and past issues of Bloodline

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