

For many hundreds of young people with type 1 and for their families, diabetes camps are a lifeline – a chance to have fun, learn, and overcome enormous challenges

Above: At Otago branch's summer camp, three friends enjoy the challenging activities provided by Evan Jamieson from Adventure Masters. hen the news came that Diabetes NZ Otago Branch's winter 2020 diabetes camp was back on, cheers went up from diabetes families all around the region.

The Southland Ski Club had been forced to cancel it because of Covid-19. But towards the end of June, as New Zealand's Covid situation looked up, branch co-ordinator Noeline Wedlock got the news that they were "all go". It means that, this September, 20 to 30 teenagers living with diabetes will once again be able to join together in Queenstown for one of the highlights of their year – the Dunedin Branch's ski and snowboard camp.

SOUTH ISLAND CAMPS

It's not the only camp the branch runs. Noeline explains that they also run a summer camp for eight to 12 year olds with diabetes.

She says the benefits of the camps are almost too numerous to list, but "the first one would be the friendships built between our diabetes youth themselves, and also the relationships built with medical staff who they'd normally only ever see at clinics". She adds that "to be with others who are dealing with the same challenges of diabetes on a day-to-day basis in this extreme environment is very empowering".

Heather Bates, outgoing co-ordinator of Diabetes NZ

Nelson Youth agrees. There, they run an annual family camp. "It supports a vulnerable part of the community who live with a serious, life-long health condition. It connects local families who might not have met before, gives the children a sense of hope, and helps build their confidence in living with diabetes. It makes them feel normal with people around them who understand the daily challenges of living with type 1." She notes that the family camps are beneficial for siblings of kids with type 1 as well. They're a sometimes forgotten group, and to be able to meet other siblings in the same boat is invaluable.

"Not everyone can make the camp, so having smaller events throughout the year keeps the group in touch and connected. Smaller social events also break the ice for the new families who aren't too sure about coming to the family camp yet."



Top right: Otago's winter camp for teens.

Other photos: Otago's summer camp for 8-12 year olds. At lower right are the Southern District Health Board's Ruth Thomson (dietitian) and Jenny Rayns (diabetes nurse specialist). Endocrinologist Dr Ben Wheeler also regulary attends Otago camps.

AUCKLAND CAMPS

Natalie Hanna from Diabetes NZ Auckland Branch says, "We try to run several different camps a year, aimed at different age groups and catering for different situations, although we're sometimes limited by funding."

Their Living Every Day Brave camp, for nine to 12 year olds, runs in January. Natalie says, "It has a component for Youth Leaders as well, with around 10 or 12 young adults attending as mentors.

"We have a strong group of youth leaders at the moment, so we're trialling having them more involved in the camp planning process. They have a fantastic insight into what it's like living as a kid or teen with type 1, having lived through it themselves. We also want the camp programme to involve more of a leadership learning component for them."

Normally, Auckland branch also runs a Type 1 Teens Living Brave camp in the April school holidays, although Covid saw it cancelled this year. Instead, there will be a day "camp" in December.

For whole families, there is a popular annual sleepover – a one nighter at Kelly Tarlton's Sea Life Aquarium. And then there is the family camp, which usually attracts about 70 people every year.

Natalie believes it's vital to have some camps that are just for young people with type 1 and others that are for the whole family. "A whole-family camp is good for kids who are younger than nine, and who aren't sure about leaving their families, and it's also for siblings and the whole family to benefit from being around others living with type 1 and to share in education sessions.

"Camps are a chance for kids and teens to make lasting friendships, and for the campers to see how others manage



Auckland children and teens enjoy a range of camps throughout the year.

their diabetes, to learn about new technology by seeing it in action, and to learn from other kids by seeing them manage their own diabetes."

Like other co-ordinators, Natalie thinks the presence of medical professionals at camp is all important. "We get fantastic support from the Starship endocrinology service. We also get lots of volunteer nurses from the Starship children's medical wards and from the community – for instance, school nurses.

"Having specialist medical professionals closely supervising the kids is essential from a safety perspective, but it's also a wonderful chance to teach them things like giving their own injections, counting carbs, and so on.

"Many kids do their own first injections at camp after seeing other kids do it – and with the time for nurses to coach them over an extended time period. My own daughter has recently started doing her own Libre insertions and site changes. After successfully inserting her first Libre, she happily remarked how she'd thought back to a friend doing it at camp – that had been over a year ago! I really thought this showed the lasting benefit of camps."

The presence of medical professionals isn't just important for the kids. "The volunteer nurses also benefit from seeing real-life diabetes management in action."

And for the campers' families back home, it's a chance to "take a break from the relentless and continuous job of managing diabetes". Natalie notes that many kids don't go on school camps independently, as diabetes management is too much for a school to take on, "so this is one of the few opportunities for both kids and parents to be independent of each other".

CENTRAL NORTH ISLAND CAMPS

In the central North Island, Diabetes NZ branches collaborate.

Lena Fendley in Tauranga explains that they run a biennial camp, but "It would be nice to run this yearly if we can get the funding. In the past, we have also sent about five kids to the Waikato Kids Camp.

"We get around 25 families coming along every time, and the 2021 camp is going to be a joint camp with Rotorua and Eastern Bay of Plenty Branches."

Diabetes Help Tauranga recently became an official branch of Diabetes New Zealand, so this will be their first camp as such. As well as having life-changing value for young people with type 1, Lena says the family camps are a huge help for parents. "At our last camp, we had a 'Break Out Session' for the parents, where we had guest speakers from MediRay and Nightscout, as well as a dietitian.

"Families found this really useful, and the children went out on activities with volunteers during this time. Next time, I'd also like to be provide a bit of down time for the parents so they can chat, get to know each other, and share experiences. This is especially valuable for new families."

Karen Reed, District Manager based in Rotorua, would like to see camps even more widely accessible in this country: "For me personally, camps have been something that I've championed ever since I was a little girl. I was diagnosed at age 10, when I lived in the UK, and I went to two camps run by the British Diabetic Association – as it was known in the early 80s.

"They were two weeks long! I learned heaps about diabetes and myself. Then, as soon as I was old enough to go to camps as a leader, I was in. I guess my first would have been when I was 17. And that was the start of my volunteering for Diabetes UK, which grew into, well, where I am today with Diabetes New Zealand."

She says, "Here in New Zealand it's pot luck whether you can attend a camp or not, depending on where you live, which is so unfair. In the UK, you can attend a camp anywhere in the country and the medical care doesn't have to be provided by your own medical team. I'm really, really passionate about making camps accessible to all kids in New Zealand, but it's a minefield of red tape."

In Rotorua, they've run several family camps, "where parents and siblings attend, usually over a weekend, and the families are responsible for the medical care of their child with type 1". However, Karen would like all children with type 1 to also have access to camps where they can attend without parents and where there is "a medical team to take care of all things medical".

She says, "Our situation in Rotorua is that we might be invited to join Waikato camps, but there is a requirement that we provide a Diabetes Nurse – and our DHB can't or won't release one. So our kids have only ever had the opportunity to attend family camps." Their next one will be the joint one planned with Tauranga in 2021.

"I'm really passionate about kids being able to go to a camp and stay away from their families. They are educational, promote the development of coping skills and practical skills. It's the perfect environment to get over fears and a great opportunity for the parents to let go a bit, not to mention have a break."



Diabetes NZ Nelson Youth and their families form a tight, supportive community, and their camps foster this.

Community

To youth from youth

Two Auckland campers offer advice to other young people living with diabetes.



f you've just been diagnosed with type 1 or type 2 diabetes, don't worry. Everything is going to be okay.

Some advice is that you don't need to panic or cry. It's all good. You'll be fine. If you come across a high, like a really, really high sugar, first thing you need to do is check your ketones.

But the really important thing is that you're still a normal human being. Don't think, I'm so different from the others. NO! You're not different. Think to yourself, I'm just like everyone else, good luck, and take care of yourself.

Mayyar Kahloon, 10 years old



alofa Lava, My name is Laylani Wendt-Fa'apoi. I'm 16, and in year 12 at Avondale College. I've had type 1 diabetes for 14 years!

I was diagnosed at the age of two and was in a diabetic coma for three nights and two days. I've had diabetes practically my entire life. I don't know any other way of living! It definitely hasn't been easy, but I have a great support network.

There will be days where you just want a break from it all, but that's completely normal. An important lesson I learnt throughout my journey is that communication is key. Communication with family, friends, doctors; it's important to talk to others when you may be struggling.

Despite having diabetes as long as I have, there were times I was hesitant to give insulin in public or in front of friends. but over time I've become very comfortable with this. The social aspect of diabetes may be something you worry about. You learn to come to terms with the questions and intrigued people. If you sometimes feel like the odd one out around your friends, you should definitely attend a diabetes camp!

I seriously recommend going. Although it's nerve-wracking, you'll feel right at home and understood because there are others going through exactly what you are. Personally, it was one of my favourite experiences, and I wish I went earlier!

I also wish I had known about the different ways of managing diabetes at an earlier stage. An insulin pump helped me go from an HbA1c of 112 to 58 in less than three months. Explore your options, communicate with your doctors and family, and find out what's best for you.

Everyone is different – it took me a while - but with the help of the team, you'll be able to figure out what's best suited for you and your needs.

Good luck on your journey with diabetes. I wish you all the best!

Laylani Wendt-Fa'apoi, 16 years old

To find out about camps in your area, go to: www.diabetes.org.nz.