

IBD Summer Camp



Camp Purple

In New Zealand, I was privileged and honoured to be a volunteer and be a part of a wonderful, life changing association that aims at spreading awareness of IBD (Crohn's disease and Ulcerative Colitis) and building strong, healthy communities of IBD 'warriors' who battle every day of their lives to join and share their story.

New Zealand has one of the highest incidence rates of IBD in the world with approximately 20,792 patients (1 in 227) and is increasing approximately by 5.6% per year, and I am one of those patients.

IBD, short for Inflammatory Bowel Disease is a autoimmune disease that can affect anywhere in the digestive tract (from mouth to rectum), in particularly Crohn's, and for Colitis, anywhere in the large

intestine. The causes are unknown, but research and examinations show that environment, genetics, and diet could've had a role in the development of this disease. Even though the cause is unknown, there is treatment.

In New Zealand, patients who are diagnosed have access to treatment that can save their lives and increase the quality of their life.

On top of the physiological pain and suffering IBD patients go through, there is also an emotional toll as well. Depending on the person and the support they have available, IBD can be a very damaging and hurtful thing to have as people can have a low self-esteem, low self-worth, anxiety, stress, depression, and even suicidal ideation.

IBD can severely decrease the quality of life of an individual, but the good thing is there is hope! There is always help and emotional support available it's just reaching out is the hard part.

But that's why it is essential to have Camp Purple and organisations like these worldwide because they offer a place where people can connect and feel normal.



IBD is a disease that tends to target young people, approximately 18-30 year olds and peoples whose lives are about to begin. But it could really affect anyone at any age and with IBD increasing and becoming more and more prevalent in our society, it has become increasingly more essential to develop treatments and services to help those who are affected by IBD.



What is Camp Purple?

Camp Purple is a camp set up by Crohn's and Colitis New Zealand to get children aged 9-17 living with either a Crohn's or Colitis diagnosis and experience a week's long camping trip.

Where is it held?

It is held all throughout New Zealand, in particular our three main cities of Auckland, Wellington and Christchurch and revolves yearly. Camp Purple usually books camping sites suitable to host hundreds of children and staff as well. There are cabins, bathrooms, kitchens, a main office, and halls.

How do children and staff arrive at the camp?

Depending on where the camp is held and your proximity to the site, children, staff, and families can drive, take a bus or take a plane. Usually, children and staff need to travel by airfare as the camp is held outside of their city and we have children that come from rural and smaller towns in New Zealand. Once children and staff have landed, a bus will take them to the camp site and a roll call will occur ensuring everyone is safe and on site. Volunteers and staff come a day earlier to ensure everything is well prepared and ready for the children's arrival. It is also encouraged that parents are not to attend the camp as the camp is aimed for children to become more independent.

Where do children sleep?

Children are divided up into age and get to bunk and sleep with people who are also their age. The boys and girls are divided and staff/volunteers also bunk with each other, divided by men and women.

What do children eat?

Children eat very 'gut friendly' foods that promote health and well being. Usually a lot of vegetables, some meats, fruits and some sauces as well. All the food is kindly and deliciously made by the chefs and is served by volunteers and some of the children. Children all sit at a hall and eat and socialise together. Children usually have three meals a day; breakfast, lunch and dinner, with snacks provided throughout the day. There is also food available for those with dietary requirements for people with allergies or intolerances and food preferences.

How big is the camp site?

The camp site is usually very large and very spacious, enough room to run, play, and explore. Camps are usually held out in nature in forests and have a very large perimeter and area. Staff usually have to ensure children are within boundaries and to supervise children where they are and what they are doing.

Who sponsors our camp?

Camp Purple is generously sponsored by our stakeholders and key partners including the FreeMasons Group and by crowd funding. Events such as a sausage sizzles and movie nights are used to help fund these events and spread awareness of the disease.



What do children and staff do?

At camp, there is a range of activities that children and even staff can do. Activities can range from swimming, rock climbing, zip lining, playgrounds, hiking, water slide, sports, and arts and craft and so much more, depending on the site and what's planned and available. We also have movie nights and quiz nights. During camp, we have a schedule and every hour we rotate to do another activity so everyone gets a turn and everyone tries what's available. There is also free play where children and staff can roam around and explore the camp site. The day usually lasts until 9 to 4 pm and children and staff then get ready for dinner and bed time, and staff have a meeting and go over the agenda and plan and prepare for tomorrow mornings activities and schedule.

Are mobile devices permitted?

Yes. But it is encouraged that children use their time to be outside and play and can only go on their devices during free play.

Do children take their medicine?

Yes. Children take their medicine generally during breakfast, lunch and/or dinner. All medication is handled and dispersed by staff and children go to the medical professionals to get their medicine. All children are treated uniquely and medication is tailored based on their needs and is taken based on what is medically recommended from their gastroenterologist.

What do children and staff pack?

Children and staff pack clothes, toiletries, sunscreen, towels, swim wear, a pillow, a sheet and blanket, under wear, and hair and facial accessories.

What if children and staff get sick?

If children and staff get sick or ill due to their illness, we have volunteer nurses that can take care and look after you but if you require further medical attention then you will be delivered to the nearest hospital for testing and examination.

How many volunteers?

Depending on how many children attend, usually a ratio between for every 10 children, there are 1-2 volunteers.

How many health professionals?

Because this camp is a special camp where children are living with a medical condition that may be life long, it is essential to have health professionals trained in giving care to IBD patients like a specialised nurse. Usually, there are two to four doctors (gastroenterologists) and three nurses and even mental health practitioners but it depends on the size of the camp and who is available.



EFCCA Summer Camp

Based on my experience volunteering in a summer camp I would suggest the following:

Location:

Camp would be ideally located in large, open, scenic, nature filled landscapes like near a forest or somewhere between the urban-rural fringe. It is important to be mindful of essential services like a hospital and a store where you can get emergency supplies but generally somewhere where it is remote but is still connected to the outside world.

Logistics:

Having a strong leadership and executive team to plan, liaise, communicate, advertise, and execute the camp. Having a CEO to manage the decisions and decide on the direction and what and how camp is going to happen and having support from volunteers to help ensure the smoothness and efficiency of the camp. This usually takes months to prepare and plan prior to the actual camp but once networks and connections are established, the process can become easier as more and more camps are organised. Also be mindful for who will sponsor and be a donor for camp as their will be a cost to renting out space, particularly camps where there are facilities like cabins, showers, toilets, kitchens, halls, swimming pools, and electricity. Logistically, it would be organised in a similar format:

- 1) Come up with location of the camp and if you want a theme.
- 2) Assemble team and delegate roles and responsibilities
- 3) Obtain financial support and funding.
- 4) Plan and manage the budget.
- 5) Find channels to promote the camp, through social media or through hospitals.
- 6) Present summer camp via video online and brochure.
- 7) Negotiate with speakers and creating a consent form
- 8) Creating a form for summer camp applicants
- 9) Creating a feedback form for summer camp participants.
- 10) Letter of acceptance form for selected applicants
- 11) Creating a schedule and itinerary for the camp.
- 12) Attendance and activity evaluation sheet.
- 13) Letter of appreciation for speakers and gifts.
- 14) Organise transport to and from camp.
- 15) Have meetings with the team and assign roles and explain the structure of camp.

Education:

Camp can be a great way to share personal stories and share information that can help increase the quality of life of each other. I would recommend having experts and people that have lived with IBD share their tips and tricks and have topics ranging from, how to communicate my IBD with my parents and friends, how to live with IBD, ways to stay healthy and active while having IBD, how to have a healthy nutrition, ways to manage my well-being, how to manage IBD in the work place, what options do I have as a IBD patient, what benefits am I entitled to, what support do I have available, and what to do during a flare up.

Budget:

Depending on the site and what prices are available, usually the standard price (in NZ) is between \$10-\$25 per child (9-17) and \$25 per adult (18+). Depending on how long you stay, and how many attendees there are, for a week it can cost about \$20,000-\$30,000 (NZD). In New Zealand however, we have generous sponsors who make it possible for camp to be free for all our campers.



References:

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