



Kids With Arthritis New Zealand NEWSLETTER August 2019

WWW.KIDSWITHARTHRITIS.ORG.NZ

KWANZ RECENT EVENTS

JULY WAS JUVENILE ARTHRITIS AWARENESS MONTH

Kids With Arthritis NZ will continue to take up the mission to make sure everyone is aware that 'EVEN KIDS GET ARTHRITIS'.

Thank you to everyone that has shared their journey and also shared and commented on the KWANZ posts on our Facebook and Instagram pages, you all helped with the July awareness campaign. We have had a wonderful response. Together we will make a difference.

Please keep your stories flowing.

Sharing is caring. It is important to not feel alone on this journey.

* **FOR INSTAGRAM** please send your article and other info any time to:-

theencourager.kwanz@gmail.com

***FOR FACEBOOK** please write your article, post it and tag our facebook name to it:- kidswitharthritisnz kwanz

The July **competition** of the 2 Wonderboom Bluetooth Portable Speakers was won by:-

© Victoria Ferguson and her daughter Amelia.

© Felix Wilton



KWANZ's RECENTLY RUN EVENTS



Teens, come sail away on Spirit of Adventure

This special 5 Day voyage provides an opportunity for physically challenged young New Zealanders to take part in an adventure of a lifetime. Thirty young people from around New Zealand, that are aged 16-20 years, come together to face challenges outside of their usual boundaries, gaining confidence and achieving tasks that previously might have looked impossible.

The annual Inspiration voyage is sponsored by the combined Lions Clubs of New Zealand, led by the Karori Lions Club.

The cost per person for the year 2020 is \$615.00. Funding may be available through the 'Halberg Trust Sport Opportunity Fund'. Visit www.halberg.co.nz for more information.

VOYAGE DEPARTS 23rd Feb 2020
Wellington
VOYAGE RETURNS 28th Feb 2020
Wellington

Inspiration voyage participants are partnered with a support person (usually one to three ratio). Support personnel are recruited from experienced Spirit volunteers who have



participated in 10 Day voyages. They offer support and personal assistance to the participants as required.

Unique voyage focuses on the following life skills activities

- building self-confidence - climbing the mast, swimming alongside
- developing leadership skills - putting up the sails
- communicating with new people
- learning to be resilient - helping clean the ship
- working in teams - rafting ashore
- dealing with close confines - sleeping in bunks

- learning new skills - sailing the small boats

To find out more out more and register your interest visit:-
www.spiritofadventure.org.nz/voyages/voyage/inspiration

PLEASE NOTE

Kids With Arthritis NZ will assist you in preparing your application. KWANZ will be your Nominating Organization

For assistance contact:- Phil Donnelly

President.kwanz@gmail.com



Many of our KWANZ children have experienced this wonderful trip with Koru Care NZ

Koru Care NZ - California Adventure

The FREE trip is 2 weeks in duration in October and the group consists of 26 children and 15 caregivers with each caregiver assigned 2 children. The Annual Koru Care California trip is for 7-14 year olds. Applications to Koru Care will be accepted at any time during the year.

Parents cannot attend.

The Koru Care application form is found on the Koru Care NZ website. On your application form please add "Referred by KWANZ" www.korucare.co.nz/california-adventure/

The group has a 3 day pass at the "Happiest Place on Earth" – Disneyland and California Adventure.

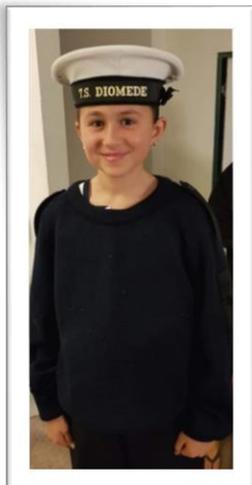
Universal Studios, Knott's Berry Farm, SeaWorld in San Diego and the San Diego Zoo are also on the itinerary.

The California Highway Patrol in San Diego and the LA Coast Guard Air Station are more fun places they visit.

With all this activity the kids have a chance to relax. They can spend the afternoon relaxing by the hotel pool or head down to Venice or Huntington Beach, they can also go shopping, Target, Walmart and Toys 'R' Us are not far away.

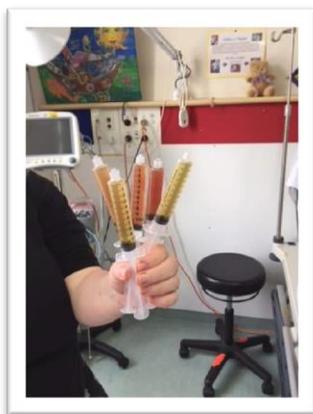
KWANZ's Young Achiever - KALEIGH

By ERANA SOPER (MOTHER)



Kaleigh was diagnosed with Juvenile Arthritis at 18 months old. Starting with a swollen knee and unable to walk, she would say, "Mummy I'm stuck". Numerous appointments later we were told she had Juvenile Idiopathic Arthritis, (JIA).

This is an autoimmune condition in which the immune system attacks the body's own tissues. Juvenile Idiopathic Arthritis (JIA) is inflammation of the joints that starts before the age of 16 years old. Kaleigh has spent a lot of her young life in clinic appointments, having procedures done to correct the swelling and medication to help with pain and inflammation.



5 Syringes of fluid withdrawn from Kaleigh's knee

We later learnt that Kaleigh was one of the few children that also had Iritis. This is inflammation and swelling that can destroy eye tissues, which can lead to poor vision or blindness. It was then we had to make the decision to place her on an immune suppressant drug. We had previously held off due to the side effects, but we didn't want her to go blind, so she started the medication. This meant an injection once a week and feeling pretty sick afterwards (this drug is also used for Cancer patients). The drug has proven to have worked, reducing swollen joints and more importantly the inflammation of the eyes.

After a couple of years we have been able to place her on a different drug which seems to have fewer side effects, although there have been signs of the inflammation returning.

Her life has consisted of many doctors, hospital procedures, medications and sickness, meaning she has missed days off school. However she has always worked hard to keep up with her peers and done well with her education.

Kaleigh is passionate about sport. She loves Hockey and is playing in the 2nd Division at school. Kaleigh is also currently training for the Aims Cross Country. Her tolerance is incredible. I remember back to her last year at Primary school when she was in a lot of pain with her ankles, the arthritis was active and the Doctors needed to drain and inject the area. The day after the procedure she refused to miss out on the cross country. With her ankles strapped up and with the Doctor's approval, she ran the race and came 1st (yes I had a few tears at the finish line). There has been several times when she has pushed pain to one side and continued, especially with her Hockey.



Kaleigh gets involved in EVERYTHING. Outside of school she is coaching her sisters' hockey team and is a part of the NZ Navy Cadets, as well as fundraising for the Vanuatu school trip. There is never a restful weekend in our house.

On occasions the arthritis has been so bad that her Dad and I have had to fight back tears. However Kaleigh is so brave and deals with whatever comes her way. Her strength, courage and determination is so encouraging, we know she likes to help others when they are facing their own struggles, we are just so very proud.

She tells me in her struggle she finds strength. I have the words, "I'm grateful for my struggle, cause without it I would never have stumbled across my strength". I love that my daughter interprets these words for her own challenges.



GO BLUE - FUNDRAISE FOR KWANZ

A great way to spread the word about Juvenile Arthritis and to support Kids With Arthritis NZ is to run a fundraising activity at your work, at your child's school, or in the community. 100% of all money raised will go back to the KWANZ children. Activities you can run could be a coin trail, multi day, car wash, sausage sizzle, GO BLUE at work, BLUE high tea, BLUE cupcakes.... Together we make a difference for our CHILDREN WITH ARTHRITIS.

Contact Robyn:-
kwanz.executive@gmail.com
OR
Mobile:- 021 1704 257

YOU MAY LIKE TO INSPIRE OTHERS AND POST YOUR KWANZ FUNDRAISER PHOTO ON OUR SOCIAL MEDIA SITES

INSTAGRAM @kids_with_arthritis_nz
FACEBOOK kidswitharthritis kwanz

Juvenile Arthritis Presentation for Schools

Kids With Arthritis NZ commissioned a video to educate teachers about the challenges that children with arthritis have when attending school.

The presentation pack that you would leave with your child's school includes a DVD and flash drive of the video, more information about arthritis in children, and details of the support that KWANZ provides.

This is an excellent resource that we would like to present to as many schools as possible. KWANZ offer support and suggestions on how to present this fantastic resource.

Contact Robyn:-
kwanz.executive@gmail.com
OR
Mobile:- 021 1704 257

Kids With Arthritis NZ Wristbands

KWANZ silicone wristbands are a great way to let people know that, 'EVEN KIDS GET ARTHRITIS'.

DESCRIPTION

The KWANZ purple wristbands are silicone with the words 'EVEN KIDS GET ARTHRITIS' and have the KWANZ website www.kidswitharthritis.org.nz

ADULT

The adult sized silicone wristbands have a circumference that measures 20cm and is 1.2cm wide. **Cost \$2.00 each.**

CHILD

The child sized silicone wristbands have a circumference that measures 17cm and is 1.2cm wide. These would be suitable for children 4 to 10 years approx. **Cost \$2.00 each.**

Place your order with Robyn:-
kwanz.executive@gmail.com



Kids With Arthritis NZ Annual General Meeting

KWANZ AGM

DATE:- 12th August 2019

TIME:- 7.30pm

LOCATION: Mt Albert, Auckland
Also by Skype

SKYPE Name = executive.kwanz

**Robyn KWANZ National
Administrator**

Email =
executive.kwanz@hotmail.co.nz

**PLEASE EMAIL YOUR SKYPE
NAME / USER NAME to the above
email address by the 10th August if
you wish to join in the AGM by
SKYPE on the 12th August 2019**

