



NEWSLETTER 2016-1

June 2016

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Welcome to the first 2016 KWANZ newsletter from Phil Donnelly

Give-A-Little

Well it certainly was a roller-coaster ride and mildly stressful but we did it. A huge 'thank you' to everyone who contributed to this fantastic result. Every donation counted whether it was \$10, \$100, or \$1,000. I certainly had my doubts that we would make it but three pretty big donations near the end meant that we reached the \$10,000 target with a day to spare! The final total was \$10,415 which is now safely in our bank account.

The Give-A-Little experience shows that a charity such as ours can generate significant support from the community which is really great and is very encouraging for future fundraising ventures.

The draw for the garden design that was so generously provided by Bayley Luutomes was won by Jess Johnson from Auckland who is a friend of one of our Auckland members. Jess lives with her sister in Auckland and has donated the garden design to her sister. The next time Bayley is in Auckland we will arrange for a photo opportunity that we will include on our website.

School Teacher Education Programme

Following the Give-A-Little success we put the development of the school teacher video into action.

Sheena Harris, our Regional Co-ordinator from the Waikato/Bay of Plenty, took the lead with this project and has done a huge amount of work to bring this together with support from her husband Nathan, our Vice-President. Thanks Sheena for all your efforts in getting the making of the video organised – we all really appreciate your passion and enthusiasm for this very important project.

Filming by Jason from Neon Mammals was carried out this week at Starship Hospital, the Royal Oak School, and the homes of two of our members in Auckland. Jason is now editing the large amount of footage to produce the first draft of the 5-8 minute video.

Special thanks to the six children who volunteered to be filmed for the video; Caelin and Moana from Waikato, Felix and Briar from Auckland, and Abbey and Storm from Whangarei. Thanks also to the National Paediatric Rheumatology team from Starship Hospital and the teaching staff at Royal Oak School.

And last but certainly not least, a huge thanks to our National Administrator Robyn Clark who organised refreshments for everyone at the filming venues, arranged the purchase and distribution of all the gifts and travel reimbursements for the participants, made her home available for filming, converted her lounge into accommodation for Sheena, Nathan and family on the Monday night, and then provided dinner for everyone (all with one foot in a moon boot!!). Thanks Robyn for your ongoing support and dedication to KWANZ.

The next step is to produce the 'presentation packs' that will include the video and other written material to be given to schools.

These resources will then be available to you, our members, to take into the schools that your children are attending. In each case we will talk with you to develop a plan for meeting with your children's teachers.

Matamata Camp Feedback

At the Matamata camp in April for newly diagnosed children and their families we did a presentation on the Saturday night and got the families to give us feedback on:

- What they wanted KWANZ to do for them, and
- What sessions would be useful at the upcoming seminars in Auckland and Wellington.

The key areas that people wanted were more information, regular feedback such as newsletters and website updates, on-line forums for children and parents, and more regular events where children/families could and develop friendships and share experiences.

We will put an action plan into place over the next month to address these issues.

Elections 2016

Each year three of the six nominated positions on the National Committee are re-elected for the following two year period.

This year the following positions are included in this election process:

National President (currently held by Phil Donnelly),
National Treasurer (vacant, Phil Donnelly in acting role),
National Events Co-ordinator (currently vacant).

As the National Secretary role is also currently vacant (Phil Donnelly in acting role), this position will also be included in this year's election process.

Nomination Forms will be circulated shortly and need to be returned by 30 June.

I would encourage you all to give some thought to taking on one of these roles so that the workload of the organisation is spread over more people.

AGM 2016

This year the AGM will be held on Monday 8 August at 7:30pm.

In Auckland we will be at the Arthritis New Zealand Northern Area office in Khyber Pass and will have Skype and teleconference links available for people outside Auckland.

We look forward to seeing a good turn-out for this year's meeting.

KWANZ 20th Birthday

The first support group for families of children with arthritis called the 'Joint Connection' was started in Auckland on 7 July 1996 by Kristin Kennedy and Rhonda Butler. Karen Derrick and Maureen Purdom took over from Kristin and Rhonda in 1999 and changed the name to 'Kids With Arthritis'. Adrienne Crowe started the JIA Support Group in 2006 in Christchurch. In 2011 we jointly created KWANZ as one group covering the whole country.

Current ideas for celebrating this milestone include:

- Stories in local community and national newspapers
- Could be combined with the launch of the schools video.
- Article in stuff.co.nz
- Need an event with a photo of us cutting a cake with 20 candles.

Any other ideas are most welcome. Just send us an email.