



Newsletter

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November, 2015

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FROM THE PRESIDENT

Over the past 3 months, the ConnecteD Board has taken a position of consolidation to ensure the ongoing direction of the ConnecteD Foundation. It is with a heavy heart and after careful consideration that the board has elected to indefinitely cancel the fundraising ball in 2016. There are numerous reasons for this, however the primary reason is strongly positioned around the format and effectiveness of the ball and the expense involved in bringing this style of event to fruition. Watch this space for future fundraising activities.

The ConnecteD board are focused on getting back to our grass roots in 2016, with an education/community day planned for mid to late 2016, along with a CTD awareness week at the Children's Hospital at Westmead. Planning is still in the early stages so if you would like to be involved, please send us an email expressing your interest.

On the **11th of November** ConnecteD Foundation will be holding the **Annual General Meeting**. All members and non-members are welcome to attend. Please note that you must be a financial member to vote or to be elected to the board. If you are interested in joining the board, please contact info@connectedfoundation.org.au

We are very pleased to have attended another successful **Cameron Sykes Sports Lunch** at the Drummoyne Rowers Club. The ongoing support of Bill McGill and his team is beyond measure in assisting the work of the Connected Foundation.

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ConnecteD Foundation continues to apply for grant funding for our **School Outreach Education Program**. We have established some strong partnerships in the process and will report back when we are advised of the outcomes. The program is due to commence mid 2016 and has a focus on developing a national school outreach program.

Lastly, we are saying goodbye to a few of our board members this year. On behalf of the ConnecteD board and the ConnecteD community we thank all of them for their ongoing support over the years and the countless hours of time to better the ConnecteD community.

Adam Heaney

CAMERON SYKES SPORTS LUNCH, Fundraiser

In September, Bill McGill hosted another Cameron Sykes Sports lunch at Ecco Ristorante, Drummoyne Sailing Club. This is a fun filled, event, honouring Cameron Sykes, Bill's grandson. Cameron had a rare connective tissue disorder.



Bill McGill, grandson Anton, and Warwick Roberts with members of the ConnecteD Foundation.

The special guests were well known Soccer player and coach, Graham Arnold as well as Soccer, Mark Bosnich. Both Graham and Mark generously donated their time. They did a splendid job entertaining the crowd. Members of the ConnecteD Foundation were delighted to attend.

The event, livened up by auctioneer Warwick Roberts, raised **\$9540**. This has been donated to ConnecteD Foundation. It enables us to continue our work with others who have connective tissue disorders



ConnecteD Foundation Supporters - Jenny Veliscek, Peter And Lynne Foxall

CONNECTED FOUNDATION FUNDS THERAPY SERVICES

It is with great pleasure that the ConnecteD Foundation announces financial support for the physiotherapy and occupation therapy services of the Connective Tissue Dysplasia Clinic, The Children's Hospital at Westmead.

We are able to fund **2.5 days of therapist hours**. This enables an essential service, integral to the school integration and whole person development for the clinic patients, to reach more people. The recipients are extremely fortunate to have the therapists who have developed specialist skills, directly related to connective tissue disorders.

CATCHING UP WITH THE REHAB TEAM, The Children's Hospital At Westmead

Provided by Dr Louise Tofts , Staff Specialist , Kids Rehab



The Connective Tissue Dysplasia Team, Rehabilitation Department, The Children's Hospital at Westmead are pleased to announce that :

- *Tracy Tate* has been appointed to the ConnecteD physiotherapy position and will start with us 1 day a week from November,
- *Verity Pacey* has returned to the hospital physiotherapy post after her two children, Crosby and Izzy who are now 5 and 3.
- *Louise Tofts* is back from maternity as well, Mondays and Tuesdays, Abbie and Alexander John are now 3 and 1 respectively.
- *Alison Wesley* our OT, who has been working hard through all these temporary staff changes, is now supported by ConnecteD 12 hrs/week which allow her to be here Monday-Thursday and provide more direct therapy to families.

The funding Connected Foundation provide to support the allied health positions is of huge benefit to families and allows us to provide much more than we can on hospital time, and we are all very grateful for ConnecteD's ongoing support.

The team is actively involved in research and education, highlights include *Verity's* recently awarded PhD which resulted in 5 publications on hypermobility related topics. You can find the publications listed [here](#)

Alison Wesley has started a Masters by Research at Sydney University with A/Prof Munns and Verity supervising.

Bianca Botha, our social work research assistant, is conducting a survey of families with arthrogryposis.

We have recently completed some work on cognitive profiles in achondroplasia and are about to start a project on physical activity in OI.

Thank you to families who have participated in these projects and we hope families will continue to support this work into the future.

We are associated with both Sydney and Macquarie universities. As such, we have students participating in projects from time to time. These are mainly physiotherapy students and we hope involvement in projects helps foster an interest in the CTD disorders in graduating physiotherapists.

We have some current changes as the National Disability Insurance Scheme (NDIS) starts to roll out – we have some families already enrolled in ACT and the Newcastle area and it has just rolled out to the Blue mountains Penrith area. The scheme is likely to be of benefit to many of our families and includes adults. Please keep an eye on the [NDIS website](#) so you are aware of when the NDIS will come into your area

COLOUR RUN: Busted But Not Broken

Rachel Evans provides the inspiring story below.

A few months ago, while relaxing at home, my sister commented that some of her workmates were taking part in the local Color Run. We started looking through photos from past events, and it looked like everyone was having a great time. The fact that the majority were also raising money for their selected charities was a great added bonus.

We soon built a team, consisting of myself, sister Jenny, her husband Graeme, and Alison, a friend I met through a medical support group. All of our team members are affected by long term health issues: myself, EDS hypermobility, Jenny is one year clear of breast cancer, Graeme suffers from arthritis, and Alison, Fibromyalgia, so we all understand the importance of timely and appropriate medical care. This made choosing a charity for our fundraising easy, it had to be ConneCTeD, an organisation that is working tirelessly to improve the fairly limited knowledge of medical professionals around connective tissue disorders.

My work colleagues from Castle Personnel, a disability organisation, soon found out I was taking part. While most know that I have a condition that causes, among other things, chronic pain, and are very supportive of me, none really knew what EDS is, this soon changed with people asking questions about how it affects me on a day to day basis, and treatment and management options. Five site managers soon sponsored the team, generously donating \$500 between them, which I will forever be grateful for.

Finally the day arrived and we joined the 15,000 strong crowd taking part. The atmosphere was fantastic, with people getting into the spirit of

things by dressing up. Among the crowds we saw numerous fairies, some 80's rockers, a family of Ninja Turtles, a group in haz chem suits, and too many onesies to count.

We had decided to have a bit of fun at the expense of our health issues, with our aptly named team "Busted but not Broken" wrapping ourselves in bandages and bandaids, although I was told I cheated as I was already covered in strapping tape.

Along the route we encountered a 'snow field' of bubbles, and attacks with coloured water and powder, with volunteers chasing people that they thought were a bit too clean. Participants ranged from babies through to their 80's, with everyone having a great time.

Finally we came to the finish line, and although I had to head straight to the first aid tent to get a badly rolled ankle restrapped, I was proud that I had made it.

Now we can't wait for next year, and to do it bigger and better!



TOP 5 SCHOOL LEAVING TIPS

From [Clickability](#)

Posted by Johanna Garvin, 20 October, 2015

Johanna is a 2011 recipient of the Joey Mittag Award and the Lionel Bowen Scholarship. She is studying Communications and Media, and hopes to work in film, theatre and social justice.



I was not very academic at school, learning wasn't easy for me. So with all these factors in mind going to university did not seem achievable. Luckily though, I have parents who have very high expectations of me and have always valued education. So, if you are thinking about going to University or TAFE my advice to you would be to do your research, plan, talk to different people at the uni's you are interested in going to.

1. Find out your options

In year ten like many people coming to the end of school I was very anxious about doing the HSC and what I wanted to do after finishing high school. I also had the challenge of teachers not wanting me to do the HSC because they felt that it would be far too difficult for me to complete. My Mum fought for me and said 'no', I would do my HSC and do pathways*. And so that is what I did. I completed my HSC over two years; the first year at school and then my second at TAFE. A few people questioned my choice of going to TAFE, but even though it was challenging at times it gave me a great taste of what Uni

would be like. No one was chasing me up on my assignments; I started to become more independent and loved this new sense of freedom in being able to choose what I wanted to do.

2. Talk to different people and find what fits you

When it came time to think about which Uni to go to I had decided to apply to the University of Notre Dame. A friend of mine had gone there and loved it. It just sounded like a great place for me to go to, it was small and seemed very focused on pastoral care. I also loved that an internship was part of the Communications and Media Course. Most importantly, Notre Dame weren't too concerned about a person's ATAR score, but more about you as a person and what you could bring.

3. It's hard... so take your time

I can still remember my first day of uni sitting in a lecture thinking "I can't believe that I am actually sitting in a lecture listening to a lecturer of all things". I have absolutely loved being a student at Notre Dame; of course it has been challenging especially in the first year when I didn't quite know what I was doing. Trying to learn to be organised and trying not to feel overwhelmed in that first year and trying to manage my study load was extremely challenging. What was particularly challenging was doing four subjects that semester. I just found it to be too much so I decided to drop to three subjects, which was far more manageable for me and a lot less stressful. It has also been rewarding and such a confidence builder. I have met some really interesting people, made life long friends, become far more confident in myself and to be honest, enjoyed going to Uni far more than being at school.

4. Ask for help and then take it

I found that the disability coordinator was able to help have things accommodated for my needs and me. I was able to get special provisions for exams, like having a reader and

writer and extra time to complete exams, which helped to make uni a level playing field for me.

5. Do things you enjoy

I have been doing subjects that I have loved. I have become more articulate and I have enjoyed being treated as an individual (pardon the cliché, but it's true). My favourite subject at uni was film studies because my lecturer was extremely passionate and as part of the subject we got to watch movies every Monday and as a result I want to work in the film industry.

Thanks to uni and the experiences and opportunities I have been given there, I have realised that I can do anything I want in life and I don't feel as anxious about the future as I once did. From my experiences, I have learnt that knowledge is power and the most important thing is to have confidence in yourself and your ability.

*Pathways describe the options available to students to gain the final school year qualifications more flexibly. Each State and Territory works differently, so speak to your school about your options.

INDEPENDENCE OVERRATED?

Some thought provoking ideas posted by Jo Berry on [Clickability](#), 16 September, 2015.



Independence is such a loaded topic. It is something I have written about before and no doubt will again. In most people there is a drive to be as independent as possible. It is rarely a good feeling to be dependent on others. I have not always had a disability and over time it is getting worse. Every time I lose a bit more function I have to work to find ways to overcome the barriers and remain as independent as possible. The drive to remain independent is massive. However it is impossible to be completely independent. It is easy to forget though that everyone depends on someone else in one way or another, some just more than others and in different ways – even carers.

What is it though that makes dependency on others such a negative? Why is it that needing help from others is often translated to feeling burdensome or annoying yet when asked to help someone else one often feels privileged to be able to assist? (Well this is my experience anyway). Knowing this doesn't seem to diminish the tendency to feel like a burden when in the position of needing the help.

Currently there is a television ad campaign running about careers in caring professions. It focusses on the fact that jobs and roles based on caring are incredibly rewarding and enriching. The ads are in my view quite beautiful and highlight a factor that we often look past – the rewards of caring for others. This is a really great message not only for enticing people to consider a career in a care profession but also for people like myself who forget that on the most part, caring for someone is not a burden but a privilege.

The decision to begin getting professional carers coming into the home to help is often a really tough one. For many it takes reaching a crisis point before accepting help beyond immediate family. The person I depend most on is my Mum and I know for a fact that burden is not a word that she would ever use but it did get to a point where my needs began

to be more than we could manage between the two of us. In my head this equalled “I am such a burden. I am too much for mum. What if she starts to resent me?” and for Mum it was “I’m failing to fulfil my role as the carer”. The fact is though that this couldn’t be further from the truth. Being overloaded with caring responsibilities can be stressful and lead to burn out. For many this feeling of needing to manage everything within the family can be damaging because it is what leads to negativity and stress for the primary carer AND the person being cared for. Sometimes accepting professional help can be the best option

Sometimes pushing for too much independence, whether the carer or the care recipient, can be a negative. It just seems counterintuitive to look at independence as a negative because it is so highly prized and strived for in our society but there is more to life than complete independence. Sometimes maybe it’s ok to settle for a happy middle ground. A HEALTHY middle ground.

A REALISTIC middle ground.

It is good to have a strong drive for independence and for achieving in life. It is just not so good when independence becomes prized more highly than personal wellbeing or relationships. It is so important to remember that caring for others either personally or professionally is quite often a very rewarding task. Feelings of burden, stress, and resentment usually only rear their ugly head when someone is overloaded and not receiving enough help themselves.

Independence is not a concept that only applies to someone with a disability or frailty. It applies to everyone – including carers. We are fortunate to live in a country that has resources such as home care and home nursing and there is no shame or failure in utilising such help. In fact accessing this kind of help can save relationships, ease strain on individuals and their families, and at the same time it can enrich not only your own life but also those who get the privilege of getting to care for you and know you. Maybe as a society we need to shift the emphasis on independence and take away the connotations of burdensomeness associated with dependence on others for both care recipients AND carers.



Jo is a trained Social Worker and a 2013-14 Ambassador for the Don't DIS My ABILITY Campaign. Since graduating university in 2010, Jo worked in community care and did motivational speaking. Jo is a Coordinator and blog writer for [Fighting Chance](#). Having a disability herself Jo feels it is incredibly important to not let a disability stand in the way of achieving a full, rich life and is passionate about helping others with disabilities to achieve the same.

BRANDON'S STORY - New Diagnostic Techniques

This [link](#), from ABC news, Saturday 24 October, 2015, tells a heart warming story of the significant effect new diagnostic techniques can have on the lives of individuals.

As a result of revolutionary advances in genetic sequencing, Brandon's treatment has changed. He is again full of cheer, walking, and looking forward to going to high school.

RECENT DONATIONS

ConnecTeD Foundation thanks the following people/communities/companies who have generously donated \$50 or more:

Anonymous

DP World Port Botany

Dr Alan Laughlan

Mrs Redelman

AD Johnson

Angela Au

AW Edwards

Malcom Elliott

Hollander Lucire

Mr Deltram

Maria Gennusa

Isabel Glasson

Mr Halmes

B McGill, via Cameron Sykes' Sports Lunch

J & B Swift

Doreen Seniors Club, Victoria

SUPPORT GROUPS

Arthrogryposis:

<http://www.taag.org.au/arthrogryosis.php>

Ehlers-Danlos Syndrome and hypermobility disorders:

Facebook group, EDSAUS

Marfan Syndrome

Vic (including Loeyes-Dietz Syndrome)

<http://www.marfanvic.org.au>

Mucopolysaccharide and Related Diseases Society:

<http://www.mppsociety.org.au>

Osteogenesis Imperfecta:

<http://www.oiaustralia.org.au>

Short Statured People of Australia:

<http://www.sspa.org.au>

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