

## Meet the newly elected National Council



At the Muscular Dystrophy Association NZ AGM in April a new National Council was voted in, some of whom had never served on the Council before. Over the following few pages we include brief profiles of each of the Council members along with their photos.

Other highlights of the AGM were a speech by the organisation's new managing director, Chris Higgins, and an erudite presentation from Dr Huhana Hickey, who is one of the new Council members and a disability law specialist. Chris outlined his beliefs in the importance of a strong national office and Council, his willingness to be accountable and build strong relationships with the branches, and his belief he could do this in an open, consultative and inclusive way. Those present shared drinks and nibbles including a large elaborately decorated 50th year anniversary fruitcake (pictured at left), cut by the former National Council chair Mary Cameron and new chair Helen Melrose.



*Chairperson, Helen Melrose*



*Deputy chair, Lindsay McGregor*

HELEN: Ten years ago I completed five years serving as chairperson of the National Council of MDA and with the support of Council members, and great staff, in particular Heather Browning and Lindsay McGregor, MDA not only survived whilst I was chair, it developed into a strong vibrant organisation with the financial capacity to move to the excellent headquarters it now owns.

Over my career and apart from my time as Chairperson of MDA I have held positions with several not for profit organisations. These include: Founding president of Auckland Women Lawyers Association, vice president Auckland University Alumni Association and president of The Retirement Villages Association (an industry based body representing owners and operators of retirement villages).

After being a partner in law firm Chapman Tripp for many years, I established my own law firm with my partner Michelle Burke. We are now a three partner inner city commercial practice with 10 staff. I served for some years on the NZ Law Society Disciplinary Tribunal which hears disciplinary matters in relation to lawyers.

I became involved with MDA after my son was diagnosed at age nine with limb girdle MD, later rediagnosed as Becker muscular dystrophy. He is now 29, and for the last three years has been living independently with the support of caregivers. My focus will be on rebuilding relationships, regaining the confidence of members in National Council and emphasising good communication and transparency, I believe that inclusive communication and transparency are important keystones of any organisation. I am committed to ensuring members have ready and affordable access to facilities, equipment and services. I believe it is important to build on the strong field worker services developed over the years within the branches.

With confidence in a united National Council re-established, my focus will be on maximising support services and funding for the services to meet the needs of our members.

LINDSAY: I have been on Council for eleven years, ten years as treasurer, so I believe I have a very good understanding of our organisation and how it can meet the needs of our members.

I am a qualified accountant (CA) and have worked in finance roles in various companies since 1972. I have been in my current company, Weston Milling, for ten years as financial controller and was promoted to general manager last September. Weston Milling is a large flour manufacturing company with four plants in New Zealand, sales in excess of \$100m and 140 staff.

I believe my business background has given me sound commercial experience which is an important aspect to assist with the governance of our organisation.

I have Becker's muscular dystrophy and whilst I can still walk (just) I need to use a wheelchair most of the time. My main leisure interest is sailing with Sailability Auckland. I really enjoy being able to compete in this sport and have now sailed in three internationally recognised regattas in Australia, Canada and most recently our own event in Auckland.

I am married to Sheryl with two adult children and live in Howick in Auckland.



*President, Mary Burn*



*Secretary, Heather Browning*



*Treasurer, John Eban*

MARY: I have been married 39 years with three adult children and four grandchildren. In 1976 I was diagnosed with MD and I joined the Association 1978. I am a manifesting carrier of Becker muscular dystrophy.

I was chairperson of the southern branch for six years and the regional representative on National Council for five years. I was appointed president in July 2008 and elected as National Council president at the recent AGM. I acted as Bow Tie coordinator for Invercargill for ten years raising around \$24,000.

I have worked as office administrator/fundraiser for the Southland Multiple Sclerosis Society for 19 years and was a volunteer for ten years before my employment. This work gives me a good background in leadership, administration, fundraising, accounting, dealing with staff and clients, local bodies, government departments and funding agencies.

I was also involved as treasurer of the local Disabled Persons Assembly for a number of years and in 1996 won a local award in recognition of my work in the disabled sector and for being a positive role model for people with disabilities.

For the past 14 years I have also been a member of a local Lions Club and have filled most of the positions at the club including president on two separate occasions.

HEATHER: I graduated as a physiotherapist in 1979 and worked for two years in New Zealand before heading to West Australia where I managed a number of physiotherapy services in support services and organisations for disabled people. After returning home in 1989, I worked for the MDA in various roles until 1996 when I went on to work in a project management role with Disability Support Services at the Health Funding Authority. More recently, since February 2001, I have worked in the role of general manager at Enable New Zealand. I have significant experience and insight into the service drivers and political mechanisms within the health and disability sectors and I subscribes to a vision of collaborative service development across social models and medical models of service delivery to build sustainable supports and outcomes for disabled people.

I am the proud Mum of 20 year old Bronwyn who is in her final year of study at Massey University.

I intend to contribute to the National Council's work in setting a clear strategic direction for the organisation. I strongly support the need to ensure that a clear vision and purpose is established for the MDA that allows it to move forward with ongoing success in supporting and upholding members' aspirations.

JOHN: My name is John Eban and I will be turning 50 later this year. I was born in Christchurch and moved to Auckland at age seven. I attended school in Auckland through to Onehunga High School. After high school I spent a year at Christchurch Polytech then joined Air New Zealand as an apprentice engineer. After a five-year apprenticeship I joined Air New Zealand as a licensed engineer.

While working at Air New Zealand I spent time in Indonesia training local engineers. While there I met my wife. I left Air New Zealand for three years and lived and worked in Jakarta, Indonesia. After that I returned to Christchurch and resumed employment at Air New Zealand.

I have four children, two girls aged 23 and 21 and two boys aged 13 and 10. My eldest boy, Tony, is clinically diagnosed with limb-girdle muscular dystrophy. He is full-time in a power chair now and is attending his first year at Burnside High School.

Tony is the reason I became interested in the MDA and I have been involved ever since. The opportunity to give something back to the community in return for the help and support we have had as a family is something I am passionate about. I believe one of the most important things we do as an association is advocacy. Often the help and support is available but people are not aware of how to contact them. We can assist by facilitating that help and support.

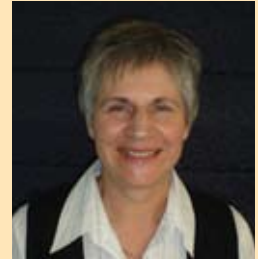
## National Council members introduced



Roger Loveless



Claire Siddens



Raewyn Hodgson

ROGER: I joined the Association shortly after being diagnosed with Beckers MD in 1990. Since then I have witnessed the changes I have experienced occurring much more rapidly in other members. This is my second year on Council, which has included attendance at the court directed mediation under Warren Sowerby in July 2008. I fully support the joint commitment made by those present to advancing the interests and wishes of the members of the Association. I also introduced Council to John Dobson of PriceWaterhouse Coopers, chairman of the board of trustees of Life Unlimited, Hamilton, an organisation that has received several WestPac Trust awards as a not for profit organisation. PWC assisted with our member survey and in the appointment of our managing director, Chris Higgins.

I am a professional engineer, long time resident of Hamilton and have recently retired as managing director of Odyssey Energy Limited, an electric power consultancy company I established in 1997. I am married to Mary, have two grown up sons and two grandchildren in the UK. I have really appreciated the support of the MDA, socially and otherwise. I would encourage members to play an active, if not physical, role in society within, and occasionally outside, their comfort zone!

CLAIRE: I grew up in Te Atatu Peninsula, West Auckland and married David in 1984 moving to Mt Eden.

My parents were told at my birth that I had a muscular dystrophy condition. What type of dystrophy no one knows and growing up it didn't hold me back in any way; instead I learnt the art of compromise and diplomacy. I got on with my life, school and friends and with the rest of my family began competitive small boat sailing and cruising in the family yacht.

I gained a diploma in design and began full-time work within the retail industry, first in merchandising then moving into the development and redevelopment of fully planned shopping centres in Auckland, Tauranga and Christchurch.

Now self employed my work is with Enterprise North Shore the economic development agency for the North Shore City Council. I work with the North Shore Business Associations, Town and Commercial Centres, Mainstreet and Business Improvement District (BIDs) programs and their members. I also contract to other Auckland associations, incorporated societies and charitable trusts providing governance and management support, coordination and marketing programs.

The skills I bring to the National Council include skills in governance and communication.

RAEWYN: I am the mother of two adult children, a daughter, Lisa and a son, Rhys. Rhys is now aged twenty six and has Duchenne muscular dystrophy. My husband and I are the main caregivers.

I have been a registered nurse for thirty two years and currently work part time in the cardiology department at Dunedin Hospital.

I have been involved with the Muscular Dystrophy Association for twenty years and am a life member of the Southern region branch. I was a branch representative for a number of years during the 1990s.

I have been elected as our branch representative to the National Council, at the Southern region branch annual general meeting held on 23 June 2009. I look forward to the challenge of representing the Southern region branch at the National Council meetings. I believe I have the skills and broad knowledge base and experience to provide effective communication/consultation and liaison between the Southern region branch members, the National Council, other branches and the national office.

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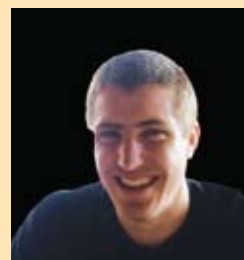
Dr Huhana Hickey



Liz Mills



Sue Robinson



Ben Robertson

**HUHANA:** I have extensive background in governance and disability human rights and advocacy. I am a solicitor. I have lead many NGO groups and I have represented indigenous disability at United Nations and international levels. My academic background is in Māori, law and disability with my qualifications being Bachelor of Laws, Bachelor of Social Sciences, Masters in Law and PhD in Tikanga Māori and Law. I have been a member of MDA for many years.

**LIZ:** My name is Liz Mills and I have been the branch rep and the chairperson of Wellington branch since November 2008, after being on the Wellington committee since joining the MDA in 2007.

I live in Lower Hutt with my husband Stuart and our two teenage daughters Hannah and Georgia.

In 1982 I was diagnosed with Friedreich ataxia and have been fully wheelchair dependent for several years. It hasn't always been easy living with Friedreich ataxia but I am fortunate to have always been surrounded by family and friends who have always supported and encouraged me through the past 25 years.

Having a good support network has made a significant difference to my life. For this reason I am actively involved at branch level and more recently as a National Council member, I want all MDA members to have access to a good support network. By having a strong branch network backed up by a well structured national office and an efficient and focused National Council, an effective support network will prosper and one which I wish to contribute to.

**SUE:** My involvement with MDA has been the outcome of having a son with Duchenne. Blair is now 19 years old and soon to be 20 in August (this is very important to him and we don't know why). I also have two adult sons who have young children of their own and Blair loves to be involved with them. Jason and Craig are involved with the care of Blair and willingly give us support when they are able to. Blair lives at home with Ken (my husband) and I. I work as a senior teacher in a community based childcare centre in Christchurch and manage a team of 12 teachers and just over sixty children on our role aged from five months to five years. (Fortunately they don't all come at once). Last year I graduated with my teaching degree - a Bachelor of Teaching and Learning. This was a major achievement in my life and one that I am very proud of. I am currently the Canterbury branch chairperson and National Council rep for Canterbury. I am looking forward to working with the new National Council and the wealth of knowledge and experience these Council members bring with them.

**BENJAMIN:** My name is Benjamin Robertson and I am new to the National Council and am very excited about the opportunities my position will give me to get involved with helping those of us with neuromuscular conditions. My youth councilor role will give me a chance to meet members of our organisation and to help them with any problems they may be having. Having a disability can be very difficult but is certainly no reason to give up enjoying life. For those of us that are younger it can often seem overwhelming with the added pressures of finding where you fit in the world. You are not alone though and many people with disabilities live fulfilling and successful lives to the point where their disability seems unimportant. If you are having trouble fitting in at school or want to talk about anything that the organisation can help with then give me a call on Ph 04 577 0377 and I will try to put you on the track to enjoying a fulfilling and successful life!