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An alliance for action

On January 29th, 2010, the Neuromuscular Alliance Queensland (NMAQ) was formed. The NMAQ is comprised of a diverse group of specialist physicians and allied health professionals as well as representatives from various neuromuscular organisations, such as Muscular Dystrophy Queensland (MD Queensland), Montrose Access (MA), Duchenne Foundation (DF), SMA Association Australia (SMAA) and other individuals.

A proposed neuromuscular clinic for Queensland

The NMAQ was formed for the purpose of spearheading the drive for a coordinated multidisciplinary neuromuscular clinic for the people of Queensland. Since its inception in January, the NMAQ has been involved in the development of a business proposal to the Queensland Government for the establishment and funding of a neuromuscular clinic at the Royal Children's and Mater Children's Hospitals in Brisbane for annual clinical reviews, as well as an additional business proposal for the funding of regular allied community clinics through Montrose Access' Corinda and Strathpine Centres.

What would a neuromuscular clinic offer?

This proposal would provide the people of Queensland with a neuromuscular clinic staffed with a variety of specialists needed to provide all aspects of care along with a paid coordinator. This would enable families with children with neuromuscular disorders to minimise the number of hospital visits required each year, with many only needing one annual visit. In addition to the annual hospital clinical visit, NMAQ have proposed that there should be regular community clinics for follow up support and care as required.

The hospital based clinic would specialise in the diagnosis and treatment of all neuromuscular conditions and would be able to provide the most current, comprehensive, specialist care available, as well as timely testing and evaluations.

In addition the clinic would foster the education of the broader Paediatric and GP network across Queensland enabling all children to receive the same level of care, regardless of where in the state they live. It would encourage care locally, with visits to the hospitals in Brisbane only when necessary. It would also pave the way for patients to choose to be part of a state neuromuscular registry and database linked with national and international registries, ensuring that Queenslanders would be able to participate in clinical trials within Australia and overseas without leaving the state.

What about the needs of adults?

While the proposed clinic will primarily serve the needs of children living with neuromuscular conditions it is the intention of the NMAQ to immediately begin work on the establishment of an adult clinic as soon as the clinic at the Royal Children's and Mater Children's clinic and the Montrose Access community clinics are established in Brisbane. The proposed paediatric clinic would facilitate a seamless transition to ongoing adult clinical care.



What can I do to help?

You can have a vital role in helping establishment a neuromuscular clinic in Brisbane by writing a letter to your State Member of Parliament in support of the proposed hospital based clinic and community based follow-up clinics, requesting them to put their support behind these proposals as well. You can also enlist friends and relatives to write as well, to show the depth of support for this initiative.

It is our belief that the stories of individuals, carers and family members living with neuromuscular conditions will be the secret weapon that will turn the tide in this struggle. Your stories are real and carry the strength of purpose and determination that can make this campaign successful.

How do I go about writing a letter to my MP?

In order to assist you in writing this letter of support, please find enclosed material and information which you may find useful in your letter writing.

These materials are offered as suggestions only. We believe that it is most important that you tell your story and show how a clinic in Queensland would have made things easier for you in your situation.

If you cannot locate your local State MP's name or address, you can access this information through our website www.nmaq.org.au, or by calling reception at MD Queensland on 3607-1800 from 9am to 5pm Monday to Friday.

How long do I have to write a letter of support?

Unfortunately, due to the upcoming Queensland budget deadlines, the time we have to promote the clinic is short. We ask, if possible, that you make this letter a matter of urgency so that the maximum impact and benefit from your story may be made upon the politicians who will ultimately make the decisions regarding the allocation of funding.

Let us know that you've written a letter

We realise that you will be contacting your MP by mail, but we would appreciate it if you would let us know that you have written a letter by contacting MD Queensland on 3607-1800 or by sending the alliance an email at info@nmaq.org.au. This will help us show the level of support for the clinic in our discussions with politicians and the media.

Thank you for helping!

We would like to thank you in advance for your help in promoting the establishment of a neuromuscular clinic in Queensland. Please feel free to contact the offices of MD Queensland on 3607-1800 should you have any questions or require assistance with letter writing.

The Neuromuscular Alliance Queensland

Letter writing help sheet

Examples of an opening paragraph:

- *I am writing to you today to ask your assistance with the establishment of a neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane. This initiative has been long overdue, and will be a welcome addition to all Queenslanders living with neuromuscular conditions.*
- *I am writing to you to ask you to put your support behind the proposal to Queensland Health for the establishment of a neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane. This clinic will provide desperately needed coordinated specialist medical care for all people in Queensland who live with a neuromuscular condition.*
- *I am seeking your support for the proposed neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane. The establishment of this clinic is vitally important to ensure that Queenslanders living with these progressive muscle wasting conditions will have access to regular coordinated clinical visits guaranteeing timely and proper management.*

Examples of Issues:

- **Issues with delayed diagnosis and/or treatment.**
 - ✓ *A centralised clinic will promote best practice in diagnosis and treatment of neuromuscular conditions.*
- **Lack of access to experts in the various fields such as neurology, genetics, respiratory medicine, cardiology, physiotherapy, occupational therapy, orthopaedic surgery, nutrition and social work**
 - ✓ *A multidisciplinary clinic will be staffed with experts in each of these fields specialising in neuromuscular conditions.*
- **Difficulty in co-ordinating and synchronising appointments, which would reduce stress and unnecessary travel.**
 - ✓ *The clinic coordinator will be in charge of organising a patient's series of visits to specialists ensuring not only the convenience to the family but also reducing the cost and time to the health system itself.*

- **Lack of access to timely testing and evaluations**
 - ✓ *An annual clinic will ensure that current world standards of review for neuromuscular conditions are maintained through regular clinical evaluation and care.*
- **A limited of knowledge and information of neuromuscular conditions with your GP or local paediatrician/physician or therapists.**
 - ✓ *The clinic would promote and foster the dissemination of information and training regarding neuromuscular conditions and their diagnosis and treatment to the broader medical and allied therapy network throughout Queensland.*
- **Difficulty in transitioning from paediatric to adult clinical care.**
 - ✓ *The clinic would foster a seamless transition from adolescent to ongoing adult care through links with adult specialist physicians.*
- **Lack of ability to be involved in clinical trials due to the absence of a maintained national database or register within Queensland**
 - ✓ *A feature of the clinic would be the establishment of proper diagnosis as well as the development and maintenance of a state database linking with both national and international registries making Queenslanders able to participate in national and international clinical trials without having to leave the state.*

Examples of a final paragraph:

- *As you can see, I am convinced that a coordinated neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane would be a great help to patients and families. I know that I can count on your support of this initiative, and so I look forward to receiving your response.*
- *Thank you for taking the time to read my letter. The establishment of a coordinated neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane is very important to me, and I am confident that you will give this matter your full support, and I look forward to your response.*
- *I trust that I can rely on your support for this proposal and funding for a coordinated neuromuscular clinic at the Royal Children's/Mater Children's Hospitals in Brisbane. With your help and support we can make this first positive step in the continuing struggle for people living with neuromuscular conditions. I look forward to your response.*

(Insert Your name, address and contact details)

(Date)

Dear (your parliamentarian's name),

The opening paragraph needs to be direct and to the point, expressing your support and seeking theirs. See "Examples of an opening paragraph" on the letter writing help sheet.

This is 'your story'. In this portion of the letter, draw from your own experience, perhaps referring to one or two (or more) of the "Examples of Issues" in bold on the letter writing help sheet. This will demonstrate the flaws that you have experienced in the current system.

In this paragraph relate how, in your opinion, a neuromuscular clinic would have prevented the issues you have experienced (examples can be seen in the responses under each "Examples of Issues" on the letter writing help sheet).

The closing paragraph should reinforce your support of the clinic, and your request for your parliamentarian's support. Make sure to ask your parliamentarian to respond to you, this will ensure that your letter will have maximum benefit. See "Examples of a final paragraph" on the letter writing help sheet.

Sincerely yours,

(Your Signature)