

Hopeworks Foundation as an umbrella organisation

1. Our Brain Hub library is an open resource accessible by all New Zealanders.

Benefits to individuals:

- * A centralised online library enables informed choices for Patients by way of access to all available options.
- * As the information is freely available online, Patients can dip into the library in a way that supports their disability , whether that be for five minutes or five hours thus reducing the current situation of either getting too much information at one time, which can lead to overwhelm, or too little information meaning unnecessary repeat visits to providers.
- * The library is created and written in a way that is easy to understand and designed for the disabled to use.
- * The library is free so does not limit who can access it
- * The directory is nationwide so is designed to include services in all areas, whether urban, rural or remote.
- * The library is user interactive which enables feedback from both Patients as well as those who wish their details to be added to the library. User feedback and tips help both patients and medical personnel understand the issues faced by those with these disabilities.
- * The library empowers the patient to know their rights and what they are entitled to before accessing services.
- * The GP and Specialist recommended database allows patients to know who is experienced and knowledgeable in regards to their specific disability. With conditions such as MND, the shortness of life expectancy does not allow for a GP to slowly learn about the condition. By either choosing a more experienced doctor, or by providing the contact details of a more experienced doctor for your own to talk to, you immediately benefit the Patient by having faster, more qualified access to care and support options.
- * By creating an interactive space for those within this sector, you create a community that is usually missing in their local area where it is less likely to have access to others in the same position. This allows not only support for the patient, but for

the families, carers, support groups, community groups and medical professionals involved. By enabling bridges between these otherwise disparate groups, you create a solid foundation for each Patient with multiple support avenues.

Benefits to NFPs, community groups and businesses:

- * Other NFPs and community groups do not need to commit limited financial and personnel resources to maintaining elaborate websites that go beyond their immediate services. They can instead refer their Patients to our site for further information.
- * Promotion of NFPs on our website extends their visibility and encourages "brand" recognition, while highlighting the services they offer to the public. By strengthening their public recognition, we hope to encourage more volunteers to their organisations as well as increasing their memberships, and thus potentially their yearly subscription income.
- * Promotion of NZ companies on our website extends their visibility, encourages brand recognition, and thus helps to strengthen their sustainability by encouraging New Zealanders to buy locally. By supporting NZ based companies, we hope to create a competitive NZ marketplace which benefits customers by minimising wait times experienced by buying internationally and additional postage and transport costs.
- * Promotion of community groups greatly assists in building additional local support network for the Patient and their family, promotes local services available that take pressure of NFPs and encourages sustainability by increasing participation numbers .increased numbers equates to increased revenue, and hopefully services that can then grow to support more people.
- * Promotion of local or national support services, such as Citizens Advice Bureau, redirect Patients to the most experienced and individualised services, taking pressure of NFP personnel who may not have the same level of knowledge or time available. Promoting them on our site assists in making their services more visible to the public.

Benefits to the medical and education communities:

- * Presently information is received by the patient in one of two ways:
 - o The right information at the wrong time - in other words, a large amount of technical and medical data at a time when the patient is emotionally overwhelmed by their new diagnosis. This unfortunately means that the

information is not being absorbed in its entirety, if at all, and due to the timing a patient usually then has many questions to ask, but must wait a long time before they can again see that Specialist. This usually results in a family spending a large amount of time and energy focussed on trying to find sources of information - in most cases information has not been given as to where families can go to find this.

- The second scenario is the wrong information at the right time. This usually plays out as a Patient going to a specialist or doctor at a time when they have accepted their diagnosis and are ready to receive information. Unfortunately the information they are getting is extremely hard to understand and more suited to medical professionals. Patients leave having no real understanding of what they are meant to do to live with this condition. The information that is hopelessly missing is those things that matter on a day to day basis and add quality of life, rather than anatomical structures. In the vast majority of cases we have worked on the very basics that are both common to most conditions, as well as being a common symptom, such as fatigue and cognitive problems, have caused them enormous distress but they have never been told to expect them. This is inexcusable and unfortunately is not well understood by medical professionals.
- Hopeworks is committed to changing this and we believe that these changes have to come from three places.
 - Re-educating existing medical professionals as to the importance of educating their patients and their families/carers on the common symptoms that they will encounter and measures they can take to minimise the impact that these symptoms will have on their lives.
 - Getting in to all medical and nursing schools and ensuring that quality of life measures are understood with a view to humanising these conditions.
 - Educating the public on what it is to live with these conditions and have a disability. If disability could be normalised and humanised, then there is a better chance of creating change.
- * Education also extends to road safety and we are committed to continuing the work we are already doing with the Rotary Youth Driver Awareness programme that is targeted at high school students. Kate has been a "Crash Survivor" speaker for RYDA for the last several years, as well as previously being a speaker for the Brain Injury Association of NZ's Education Advisory Service which spoke with medical students and professionals predominantly. Kate was also asked to speak to Mt Albert Grammar as their nominated "Hero in the Community".

- * The Brain Hub library has a section entitled Youth Education that is aimed at getting both government and private education initiatives to the public. By having these resources online, educators and the public can use this information independently or in collaboration with Hopeworks or other agencies.
- * Benefits to government include the circulation and reinforcement of their messages to the public, and access and direction to more of their resources.
- * As Hopeworks is designed to "fill the gaps", we are able to identify to service providers where changes could be made that would benefit their Patients. We have already begun this process with talks to Auckland DHB and this is a real focus for us. We believe that communication is usually key to breakdowns in service provision and Patient satisfaction. By being an agency that advocates communication between parties, we feel we can make a positive contribution in these areas.
- * Hopeworks clients are a great resource for continuing education. Like Kate, they are motivated to turn traumatic experiences in their own lives into opportunities to share their knowledge and humanise their experiences. This will be an enormous asset to medical professionals in that they will have access to Patients with a wide array of neurological conditions who are willing to give up their time to help others.

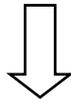
Benefits to sponsors, grant holders and partner organisations:

- * Hopeworks, as above, is committed to creating positive and long lasting change in New Zealand. In addition to the obvious benefits to Patients with these conditions, the impact extends to the families and carers by way of a higher level of support and information and stronger foundation from which to assist these Patients.
- * By supporting local communities and charities, it enables them to focus on what they do well - primarily field worker services - rather than spreading themselves and their resources too thin. Local community groups that help this group of people, with the right support, can grow to help others with different conditions or difficult circumstances such as isolation, poverty and lack of social support. This has an immediate ripple effect on local communities coming together to support each other. Local community groups also offer an outlet for the families of those with neurological conditions, where they can be the centre of attention in a life where they often have to come second. This offers them a chance to grow outside the shadow of these conditions. Lastly local community groups offer a place where people can meet others with the same conditions and share resources, stories and experiences. As mental health problems are almost inevitable amongst these groups, a safe shared setting can allow a release and a foundation of support from others.

- * For local businesses or companies with a community focus, enabling the development of healthy community groups has an immediate benefit by way of public perception, potential buyer loyalty to that company and access to the community for which a company is trying to build relationships.

- * Because of Hopeworks goal to build bridges between all sectors, grant holders, companies and sponsors can benefit from a pre-built network of likeminded people. Because Hopeworks is about collaboration, rather than competition, this paves the way for others to join in this partnership in ways that benefit everybody.

Following diagnoses, new clients are directed to the Hopeworks Brain hub Library - at www.hopeworks.org.nz



Here they can access information on:

Care & Caregivers

Entitlements

Recommended GPs & Specialists

Support Services

Treatment Services

Their Rights

Education

Leisure & Travel

&

Resources

Full information, service descriptions and contact details are provided for all local:

- Non-profits
- Community groups
- Medical service providers
- Local businesses, and
- Care Agencies

Where:

- a service cannot be found
- a client is overwhelmed
- a gap in the system prevents help
- a person is not being treated fairly or
- a client wants more individualised assistance

they can contact us and we can help them resolve those issues, support them through the process and take the necessary steps to empower them as they move forward.