



**BRIDGES &  
PATHWAYS**

beyond chronic illness

ABN 29 248 878 249

*'Consumers & Providers working together to improve services'*

P.O. Box 793, Blackwood, Adelaide, South Australia 5051

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Charitable Licence No CCP2731

## **Bridges & Pathways E-News – May 2017**

**Thank you to all the proactive Change Champions working for ME/CFS and/or Fibromyalgia.**

It's now time to establish the: ***Specialist ME/CFS and Fibromyalgia Multidisciplinary Demonstration Clinic and Centre of Innovation***, right here in Adelaide.

Work for the new Clinic progresses daily, many of us are becoming excited and a little impatient. As we mentioned in our last E-news, recruitment for Clinic staff and research is continuing, and the patient waiting list is growing.

Remember - Registering for the waiting lists is important for 2 reasons:

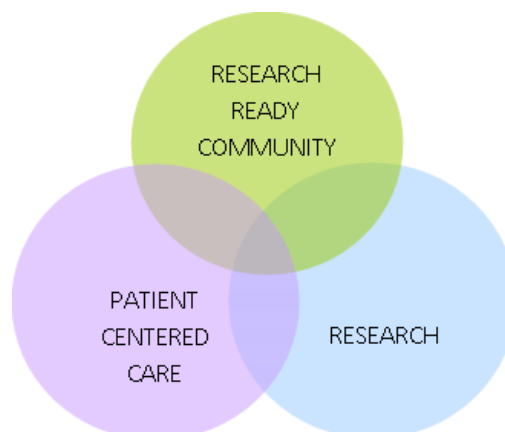
1. We need to be ready to go: which means we require staff appointments to be fully booked to cover salary costs.
2. The numbers on the waiting list are important for advocacy and fundraising, greater numbers reflect greater need.

Most recruitment has been through General Practitioners, this means we also have a growing list of providers who will receive regular updates and information to use in their own practices.

### **Research Ready Community (RRC)**

Yes, this list is important too. The Research Ready team is a cross-section of people that are at call; ready and available to participate in projects, and be kept up to date with the latest information and research findings. You will be able to discuss participation with your doctor. In the past we have missed valuable opportunities because we only had 24 hours to contact people to participate in validating a biomarker or test. Having interested people already registered will allow us to maximise opportunities as they arise.

**If you would like to be available, contact the RCC Project Coordinator at [bpclients5159@gmail.com](mailto:bpclients5159@gmail.com)**



*Participate in research that makes a difference*

#### **Consumer Workgroups include:**

- Telehealth & wearables
- Marketing & fundraising
- Research & data collection
- General Practice / Peer Support
- Health Educators
- Consumer Representatives / advocates



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### POSITIONS VACANT - VOLUNTEER TEAM:

Volunteer / Work Program / Field work  
Fundraising Marketing promotions  
Computer programmers  
Telehealth setting up  
Office (Experienced) / Office Admin  
Facebook / Social Media

Researcher to review new research  
Crowd Funding  
Grant writing  
Group Leaders local & SKYPE  
Volunteer Work Coordinator  
Clinic team

### CROWD FUNDING AND DONATION OPPORTUNITIES

While our 'fundraising goal' for the full clinic project over 3 years is \$600,000, we have broken the projects down into achievable steps as requested. You may have another area you would like to fund, please let us know.

- **Telehealth / Digital Health** - 24/7 Support for Rural and house bound clients (\$300 per month)
- **Microbiome Research** - \$100,000 Ready to go - funding grants unsuccessful
- **Fatigue Biomarkers / Functional Mitochondrial Testing** - \$100,000 for pilot, but if we can raise \$20,000, another funder will cover the rest.
- **Medical Care** - \$2,000 per patients (Gap between Medicare & actual costs)
- **Researchers Salary Costs** - \$80,000 per year
- **Student project** - 6-monthly, expenses only (\$2,000)
- **Pre-appointment case assessment** - \$120 per patient (45 patients in pilot)
- **Wearables** - \$300 each (45 patients in pilot)
- **Health educator trainer** – 3 hours per session (\$180 per session)

### GROUPS – LOCAL, PHONE & SKYPE

One of our original tags was:



**T.E.A.M. Together everyone achieves more.**

**Can you help?** Past experience shows that every group needs a regular core of people to run it, not just one leader. We become friends, walking together and never feeling alone. Many of our groups continue to have waiting lists.

**Aberfoyle Park group** meets the first Wednesday of the month.

### Fundraising and Awareness

**Remember: Donations** can be made through a Bank transfer:

**Account Name:** Bridges & Pathways

**BSB Number:** 805-050

**Account No.:** 2359845

Please send a copy of the receipt and contact details via email to [bpprojects02@gmail.com](mailto:bpprojects02@gmail.com) to receive a tax receipt.