



The BRP Alliance

Vision and Organization Plan

www.BRPalliance.org



Vision



- ▶ Create a community for Patients, Physicians, Researchers, and Advocates to freely collaborate on study, diagnosis, treatment, and cure of BRP.
- ▶ We are all volunteer, independent from any outside organizations, and our mission is to create better awareness, diagnosis, research, and treatment for Brachioradial pruritus (BRP) and neuropathic itch.
- ▶ We are, at core, a Patient Advocacy community, who aspires to work in serious partnership and scientific collaboration with the neurological research community and the medical treatment community.



Situation



- ▶ There is little to no scientific consensus how many suffer BRP. While one study suggests there might be millions of us in the USA alone, we are considered super rare.
- ▶ BRP does not even appear on the 480 rare diseases at raredisease.org, they are offering training and support to our organizers.
- ▶ BRP is relatively new and almost certainly under-diagnosed. Exuberant patient interest. 2000 joined three Facebook support groups. The common theme is that medical professionals are unaware, mis-diagnose, lots of horror stories.
- ▶ BRP is an orphan disease, falls through the cracks of neurology vs dermatology. Under-studied, misdiagnosed, little published interest in the research community.



Problems Needing Solving

- ▶ Public Awareness: BRP is virtually unknown.
- ▶ Physician Awareness: Incredibly low. BRP patients consistently report misdiagnosis as a dermatological or psychological issue.
- ▶ State of Research: Large gap scientific knowledge. The BRP community is small and silent, our nightmares mostly unheard and unknown, even in the neurology research community.
- ▶ BRP Patient Advocacy: Besides the three Facebook peer to peer support groups, there is zero organized effort to call for better BRP research and treatment.
- ▶ BRP Patient Wellbeing: BRP is under-reported and so debilitating that it causes suicidal ideation, affects families, and destroys quality of life. More research and support needs to address the emotional aspects of chronic neuropathic itch.



The BPR Alliance

- ▶ An open letter was circulated in the three BRP Facebook groups. Response was unanimous in support of organizing a patient advocate community and web site. Dozens have volunteered for some level of involvement. Not a single negative reaction. People want hope.
- ▶ Decision makers at world class neurology institute and America's oldest science magazine both recommend the name BRPAlliance.org as a credible name that suggests the free and open exchange of info.
- ▶ Volunteers have donated, secured the URL, and are creating branding and a web site for The BPR Alliance at BRPalliance.org



Aspirational Goals



- ▶ The BRP Alliance will organize as a Non Profit Corporation.
- ▶ We aspire to the purity of an all volunteer organization. There will never be any dues and fees for membership. Transparent finances.
- ▶ Our core mission is to provide hope to, and advocate on behalf of, BRP patients. We accomplish that by bringing together, embracing, informing, and collaborating with various medical and scientific organizations and individuals.
- ▶ Revenues might be in the form of donations, grants, advertisements and sponsorships.
- ▶ While we are committed to credibility, we propose to have fun and enjoy fellowship every step of the way as we collaboratively embark on a noble mission to try and get some relief for those going mad with BRP and other neuropathic (but not neurotic) itches.



Who are We

- ▶ Working Committee Chair Denis Eirikis: Science writer, BRP sufferer, nonprofit communications expert, experienced in lobbying and development. “I am shocked at the lack of research and awareness, I recently retired as president of a PR and Governmental Relations firm ClearLightPR.com
- ▶ Co-Chair: Nikki Wheetman: Health care professional in UK, Administrator of the world largest BRP [online support group](#) with 1600 members
- ▶ Angel Tansley has volunteered to chair the web committee.
- ▶ A dozen or so have expressed interest in volunteering. We have immediate needs for people to step forward for committee chairs. Need an organized people person cat herder to start chaining volunteer committee.



One Year Vision



- ▶ Robust web site as world's best repository of BRP info. The web site will arm BRP patients with tools to make their doctors and communities more aware featuring social media friendly downloadable fact sheets, brochures, presentations, videos and other awareness and engagement tools.
- ▶ Incorporated. Volunteer WORKING Board of Directors. Separate Emeritus Advisory Board of Neurologists, Dermatologists, Researchers, and other related professionals
- ▶ Launches two major initiatives in first year:
 - ▶ Tell Your Story Campaign or even Contest. Aimed at patients.
 - ▶ Medical Professional Survey Campaign:



Tell Your BPR story internal campaign.

- ▶ Qualitative anecdotal survey designed to:
 - ▶ Engage patients, give them a voice, hope, and volunteer opportunity.
 - ▶ Our stories are who we are. They are what empower us. We will use our stories to create awareness, put a face on the disease, All people who agree will have their stories professionally edited and displayed on the web site and in our social media. Each person sharing their story will be given a choice of anonymity or visible ambassadorship. We can even spin it as a contest with prizes for best stories.
 - ▶ Our stories are marketing gold. They will be mined for details of the anguish of this disease that only you can provide. We can use your stories to attract awareness, sympathy, and maybe even data useful to researchers ***

*** Example: This first patient survey will be open like essay test because we aren't smart enough yet to know what to ask. For example, 3-4 volunteers happened to all have the same blood type. There's probably no correlation but I never would have thought to ask this. Lets cast a wide net for stories that researches can see, and they can help us develop more scientific surveys later.



Researcher/Physician SURVEY CAMPAIGN

- ▶ It will be an “educational” survey. Everyone talking it becomes aware of BRP
- ▶ We make the survey quirky, newsworthy, something science media might pick up. We name it something fun like, “Take 60 seconds to complete this “Dante’s 8th rung of hell Deep Arm Itch Survey” and get a chance to win this fabulous free prize and maybe even advance the science on neuropathic itch.
- ▶ We partner with medical societies, neurological societies, to advertise our survey to their members. I’ve done something like this before and know how to do it. I am already recruiting organizations that will help us spread our message.
- ▶ The survey is our initial gambit in creating a database of BRP researchers and medical professionals, the exact people we want to educate and influence.
- ▶ We want to ask every single BRP patient to insist their physicians cooperate and maybe recruit them to help spread the survey to their local medical peers.



Next Steps

- 1. Create a working committee, and a working committee Facebook page for online collaboration.
- 2. Identify and recruit our leaders. We need committee chairs for the working group. Ideally, folks later willing to take positions on our board, such as whoever chairs our start-up Finance Committee should ideally be open to serving as our Treasurer.
- 3. Create BRP web site,



Immediate Volunteer Opportunities

- ▶ Secretary/Membership Chair/Volunteer Coordinator/Admin: Organized people overseeing volunteers and our various rosters and organization charts. Right now this job is helping visionary me organize and figure out who is doing what. Your deliverables eventually will be our org chart, membership rosters, maintain our various databases. We need a Committee Chair soonest.
- ▶ Story Editor/Archivist: You will be in charge of editing and organizing our stories. You need attention to detail as our stories will be two kinds: anonymous and attributed. I have this idea of launch our web site with the names, at least, if not the stories, of at least 100 BRP Alliance “members”.
- ▶ Licensed Medical Advisor



Immediate volunteer needs (continued)

- ▶ Need Finance Chair
- ▶ Need legal/advice
- ▶ Licensed Medical Advisor and Medical Committee: We need all our content and links to medically/scientifically vetted. Make sure patient stories we choose to publish don't include bad medically unsound advice.
- ▶ We need all skills, all sorts of people, and good committee chair to harness this wonderful energy and ideas.



This Posted as Framework for discussion

- ▶ Its all flexible.
- ▶ My hopes are: Working group seriously starts work this week using the Facebook page.
- ▶ BRPAAlliance.org goes live with some content for working committee in a week or two. We wont publicize until it gives favorable and credible first impression. Shoot for December 1?
- ▶ Incorporation First quarter 2021 as 501c3 nonprofit headquartered in Palm Beach County Florida, home of worlds largest philanthropy community as well as home to one of the world's foremost biotech research clusters which includes world class neurological institutes with numerous Nobel prize winners. These are the smart people we want to engage, interest, and ask for help.



A personal note

Dante's Inferno featured nine increasingly miserable rings of hell. The 8th rung of hell was described as insatiable itch. This BRP is maddening. You are not alone.

I used to be a highly paid and skilled champion of causes. I was a scientoist who learned to make my living as an champion for hire, \$130/hour, mostly green clients. Then, for health reasons I retired too early which was a mistake, I became bored and depressed. I asked God for help. Isolated in pandemic, I prayed for a mission. I was a champion without a cause.

I now have BRP. I have been in the chronic pain support community for years, I testify neuropathic itch is worse. I am shocked and aghast at how low the bar is on public and professional awareness. We are misdiagnosed, uncounted, marginalized. By experience, I know exactly how to change that.

If we work together, I see a light at the end of the tunnel. My promise, if you join this effort, is that your involvement will give you hope. We are aiming high. Shaking trees. Demanding attention. It will take all of us. MY hope is that the web site is launched with the names of at least 100 of us as original signatories to the BRP Alliance. Please join us.

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