

A Unique Approach to Providing Quality of Life

John Herd

Something very unique has been taking place in the chronic fatigue syndrome (CFS/ME) community and it reached a magnificent crescendo in September.

For a lucky group of people who have CFS/ME the isolation that the illness can impose has been lessened by an idea Alison Petty had two years ago. She has been living with the illness for the past ten years, but is currently improving significantly after having had a severe CFS/ME relapse three years ago.



Alison created an Internet based organization and web site she named the Brainfog Association (www.brainfog.org) - the name reflecting the cognitive problems so common to this illness. The site is a place where those afflicted with CFS/ME can partake in fun socialization and friendly support - sharing aspects of life that can feel out of reach when partially or completely homebound. Though members may be hundreds or thousands of miles apart, very meaningful friendships abound in

the Brainfog Internet community - it feels like a warm on-line living room.

The words "fun" and "socialization" are both central components of the on-line community's driving philosophy. Unlike many CFS/ME web sites that encompass discussion of research, treatment and political matters, often leading to divergent views and sometimes discord, the Brainfog.org site has always had a wonderful atmosphere because of its pure socialization and support orientation.

This year Ally and a group of volunteers brought her brainchild to the next stage of its metamorphosis by arranging a large gathering of Brainfog members at the base of Mount Snowdon in Wales, UK. But "gathering" does not come close to describing how very unique the Snowdon event was in the history of CFS/ME or how magnificently wonderful it was for participants. The Snowdon gathering was planned to be an extension of what has been created as the Brainfog community, a stripping away of the thousands of miles of computer and phone cables.

As far as I know, never before in the history of CFS/ME has a large group, especially such a large group, approximately 60 people, come together for purely a socially sharing. It was a celebration of living, friendships and sharing the feeling of grasping some of the living that can feel so out of reach when one has CFS/ME.



An entire Youth Hostel facility called Bryn Gwynant which is situated at the base of Mount Snowdon in Wales was obtained for the gathering. A more magnificent setting could not have been selected. The hostel arrangements and activities were all planned so members could pace themselves, participating at their own levels of ability.

Prior to the gathering most couldn't help having thoughts of "How could I even get there?" and "How could I survive all those days with so many people?" It worked though and it worked wonderfully. Most came with caregivers or partners to help them and share in the experience. Many traveled with other members. Getting there and sharing in the experience was very much an "all for one and one for all" type of experience in which everyone was looking out for and helping each other. When anyone needed help with anything there always was someone there to help.

Each time another Brainfogger arrived at the hostel it was absolutely surreal. Though many had already forged friendships via cyber text and possibly phone calls, most had not previously met. They had not shared the real hugs or seen each other's smiles. Seeing that happen and sharing in it was spectacular. All the arrivals lacked was French horns, but the repeated waves of excitement and joy with each new arrival was the stuff of life long memories.

As an observer and participant one of the most thrilling things to see were all the individuals' satisfaction and joy from just being able to be there partaking in the experience. How different this kind of quality living felt compared to the survival mode type of living that the CFS/ME usually imposes. "Absolutely brilliant" would be an understatement.

Throughout the days participants gathered in small groups in the Hostel building and grounds. People could usually be seen napping on couches or heading off to their rooms for some quiet time while others socialized and went off for excursions into the surrounding area. At meal times some had the provided meals while others either made their own meals due to specialized diets or had assistance in doing so from caregivers or other members. Planned activities during the gathering ranged from a welcoming and cookout to a raffled, arts and crafts activities and a train ride that enabled participants to get to the top of Mount Snowdon.



Being all together atop Mount Snowdon was a tremendously inspiring iconic kind of experience. It was entirely different from the usual CFS/ME living experience. Standing at 3,500 feet in the wind and beauty felt as if it was a huge accomplishment, a milestone in participants lives. But most exciting was watching those who were more strongly effected by CFS/ME. What they were feeling could be seen in their sparkling eyes and tremendous smiles - all smiled for them and with them. It was a truly liberating and empowering experience for both the Brainfog members and their caregivers.

On the last day of the gathering a soap bubbles blowing ceremony was held overlooking the nearby lake and the Snowdon mountain range. Each bubble blown was a heart felt remembrance of all those Brainfog members who were unable to attend, and everyone worldwide who is living with this illness.



Many CFS/ME organizations have provided invaluable support groups, information resources and conducted advocacy efforts over the years. The Brainfog Association is the first though to focus solely upon giving patients back a bit of the social lives and fun that may have been lost due to the direct and indirect impacts of CFS/ME. Due to the enormous success of the Brainfog website and of the Brainfog Snowdon gathering I suspect and hope that this most humanitarian of services will become a growing movement. It is the very best of people helping people and a glowing glimpse of how even when life has become very difficult there can still be quality of life.

To reach the Brainfog Association website go to www.brainfog.org

Copyright John Herd, 10/03 johnherd@johnherd.com