

# Youth and Adult Forums – World Congress, June 2010

## **► Feedback from the Youth Forum**

*David Proud*

- Members felt they lacked confidence in regard to self image. This affected how they felt about image and how they thought they were perceived by others.
- Members expressed a fear of exercising in public places due to low self esteem. Access to fitness and sports facilities was difficult.
- Continence played a big part in lowering confidence. Members wanted to be independent. This included being able to manage their own continence issues.
- Members expressed that transition from teenage to adult was a lonely process. Specialist advice and access to support was still needed.

### **Major Issues:**

These issues affected all ages and both forums.

- The female members spoke of increased need for healthcare advice and access to specialists. We believe this to also be a problem with our male members but they were less vocal in expressing concerns.
- People spoke of not believing doctors appreciated that they wanted a life. It is different for a doctor to help you live, than to have a life.

### **Recommendations:**

- The forum recommends holding a pre-conference before next years World Congress. This will allow forum members to also listen to medical professionals deliver presentations.
- The forum recommends the next step is to continue to listen to people with spina bifida and hydrocephalus, ensuring they influence your next step!

## **► Feedback from the Adult Forum**

*John Fulham*

- As we are only now experiencing older people with Spina Bifida, this is the first generation in terms of assessing needs. We have a blank canvas to work with.

- Medical Care featured strongly in the Adult forum and in particular the lack of good medical care which focuses on the person.

- There is a lack of expertise and knowledge in the medical profession in relation to care for aging people with Spina Bifida. We need to work with the medical profession to upskill and develop these skills.

- A more holistic lifetime approach to medical care is required, one that takes into consideration the person and not just the Spina Bifida. This needs to include focus on such issues as:

- Body Aging - joint impacts etc
- Ulceration
- Skin Care
- Continence and changes in body behaviour
- Gender Specific Healthcare requirements

- Taking Control and Self Help featured strongly. We need to start utilising the resources available to us. We have role models which we can use to assist, guide and mentor others along their path through life. We now have members who have been there, done that, have the t-shirt, even if the t-shirt may not fit them anymore!

- We need to change our expectations on life. We need to focus beyond the medical to encompass the overall quality of life, concentrate on living, healthy lifestyles and achieving potential

- We need to help our organisations, not just expect services but get involved and deliver. You are

your organisation!

- We need to tell our stories, share experience and manage our own needs
- Concentrate on the person, not just the disability.
- Education. Provide continued focus on supporting parents with children who have Spina Bifida.
- Focus on Education, Teachers in mainstream to give them the support they need to support our children for integrated education.

**► Youth Forum Speech**  
***Jennifer Fitz-Roy***

“As young adults with spina bifida, we all too frequently encounter individuals who simply don’t know what spina bifida is. Of those individuals who have heard of spina bifida, they often have extremely negative perceptions of our disability.

Awareness about the role of folate in preventing spina bifida is extremely important, but awareness about what spina bifida is and creating a positive public perception of spina bifida is equally important. The world needs to be aware of the importance of folate, but the world also needs to be aware that people with spina bifida can lead full, meaningful, and productive lives. Programs to enhance our quality of life, empower us, and develop our advocacy and leadership skills are equally important to promoting the prevention of spina bifida.

Youth with spina bifida want our disability to be seen simply as a part of who we are, not something to be feared or avoided. We do not want to be pitied or thought of as less fortunate, but rather to be given each and every opportunity to flourish and fulfill our unique, personal potential. Having spina bifida makes us different, but our lives have value and they are worth living. In sharing our challenges and struggles, we hope to create a world in which we have access to education, employment, healthcare, transportation, socialization, and recreation that is equal to those of people without disabilities. We want to help create programs and policies that enable us to achieve our optimal quality of life.

We celebrate the ways in which having spina bifida has been a positive influence in our lives and helped us to become the individuals we are. In our eyes, the next step is to change attitudes and perceptions about spina bifida. Having spina bifida does not define us, but it is a major part of who we are. We hope for and work towards a day when having spina bifida never limits us from achieving our goals but instead is something we celebrate for the diversity it brings to the entire world”