

Albinism Fellowship

Dream BIG Feedback

Background

At our 2009 conference, It's Time 2009, we invited delegates to attend a workshop, which we called Dream BIG, to help inform the future direction of the fellowship. We subsequently invited other members to do the same through our website.

We asked people:

1. What do you think of our key services?
2. Which of our services do you most use and why?
3. Which of our services do you least use and why?
4. Is there anything we should stop doing or something else we should start doing or do more of?
5. What do you most value about the organisation?
6. What do you think about our name?
7. How do you mostly access & interact with the albinism community?
8. What do you want Albinism Fellowship to look like in approx 10 years time by 2020?

We also asked a range of appropriate follow on questions.

We received responses from seven groups at the conference and two individual responses afterwards.

Comments were wide ranging and did not always follow the order of the questions above. Therefore, the key messages have been summarised below under the following headings:

Phone & email helpline

There was very little mention of the help lines in the responses. Where people did feedback their comments were very positive, especially about the phone line as a first point of contact. The odd person was not sure about how to access the phone line. There were several comments indicating some uncertainty about the help line service.

Albinism Life magazine

There was overwhelming support for the magazine continuing in print and arriving on people's doormats. Some people recognised the value of also providing the magazine by email or having a more frequent e-newsletter. There were very positive comments about the content including the positive 'feel'. Some suggestions were made on how to improve the content. These included:

1. Using the magazine to raise the profile of contact persons with bits & pieces of news from local areas.
2. Developing a children's page perhaps with competitions etc.
3. Making it clearer how to write articles for and contribute to the magazine and the copy deadlines.

Advocacy work

There was some feedback about and recognition of the importance of advocacy work. There was feedback for us not to protest overtly about negative portrayals about albinism as this could be counterproductive. People felt it best to get positive messages across. One suggestion was for more targeted advocacy for children. We have an opportunity to develop more information resources to support advocacy work.

On line resources

People like the on line resources and want to see these develop further. They want the website updating more often and for it to be more interactive. People want us to develop our wider on line presence especially for younger members. They feel we should allow easier access to contact persons via the website.

Local and regional events

There was strong support for continuing and developing the number and range of local and regional events. People want more information about all events more often and for the marketing of events not to be restricted to certain geographical areas. There were many comments about the value of the personal contact that comes from these events.

Conferences

There was overwhelming support for this event. People recognise the value of meeting face to face and think this is central to the fellowship's work. Whilst some would prefer more frequent conferences most recognise that every 2-3 years is most appropriate. There was strong support to continue these events.

Fellowship name

Whilst a few people recognised the potential for assumptions to be made about the religious connotations to the word 'fellowship' there was majority support for retaining our existing name. People felt that fellowship described the organisation well e.g. friendly and supportive. There was some support for more education to change understanding of albinism versus albino.

Paid role

This was not discussed extensively. Where it was views were split pretty equally between support for a paid post, or paying to outsource some activities, or recognise voluntary input through honoraria or to retain the voluntary focus of the organisation.

Other feedback

There were several suggestions made that may help us in developing some of the above areas of work. These included reviving our business card, developing standard information packs e.g. for schools, and arranging activity weekends. Other key points of feedback included:

1. A youth representative to travel to support international initiatives (e.g. donating sun hats to schools supporting children with albinism).
2. Developing ways of people giving advance consent for their contact details to be shared with other members.
3. Developing more listening services in addition to contact persons to provide more individual support where necessary.
4. Reaching more people from black & minority ethnic groups. There were several comments about the substantial numbers of people we are not reaching in these groups.

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