

Chairperson's Report for the year 2004 - 2005

This has been a year of new beginnings for the Turner group.

For many of our old members, we have become the gatherers and providers of knowledge, of news in our newsletter, and of comfort during the hard times. When things are going well, some of our members seem not to want the same level of contact with the group.

For this reason the group cast about this past year, searching for areas we could be of most help to society.

One project has taken much of our time. We have been in intense negotiation with SAIDA, Wits genetics the Donald Gordon hospital and selected doctors, over our plan to start a Turner Syndrome clinic. We have managed to raise enthusiastic support for this venture. So far SAIDA and Wits genetics are working with us on the idea. We have met with Donald Gordon and they are agreeable. We have approached some of the doctors we will need. They are also keen. Just some further details must still be ironed out. We will be continuing with this project in the new year.

The idea was born after a British speaker described setting up such a clinic at the last international conference. This emphasised for us once again the importance of retaining our links with the international Turner community - for the exchange of ideas and the new international research.

The aim of the clinic is to make the lives of TS girls and women easier. The clinic, which will run once or twice a year, will provide a one-stop-shop where the emphasis will be on wellness, and managing the condition for the maximum quality of life. Health professionals with an interest in the condition will be there on the same day - such as endocrinologists, gynaecologists, psychologists, genetic counselors, ENTs, dietician etc. Without such a clinic, Turner girls and women are often forced to take time off to visit these professionals separately.

It will form a national centre of excellence in Turner treatment. People from outlying areas will be able to come once or twice a year, and carry instructions back to their doctors at home. This will also spread information and knowledge to health professionals in smaller centres. The cost for seeing a number of specialists in a day will be minimal, and be sent directly to the patient's medical aid. Those with no medical aid will not be charged. This has been agreed with Donald Gordon, which is a Wits University facility.

The clinic will also provide an ideal venue for research into TS, which has been painfully lacking in South Africa.

Our other new beginning is a pro-active attempt to reach Turner girls and women in disadvantaged communities. While we have always welcomed members from every sector of society, somehow we have never been that successful at drawing great numbers from any but middle class communities. Despite the fact that South African society is now free, we are still divided. For this reason we felt it necessary actively to reach out into other areas.

We composed a simple pamphlet, which we then raised the money to have translated into isiZulu, isiXhosa, Sesotho, Sepedi, Setswana, Xitsonga and Tsivenda. We chose these languages on the basis of advice we were given from the translation service used by Wits University.

We raised some money towards printing these pamphlets from two drug companies, Novo Nordisk and Eli Lilly. But we have now managed to interest the Department of Health, who are working toward giving us access to educational funding which could be used for their printing. This has the added advantage that they will use them, and distribute them to all clinics and genetic sisters. We also hope to place them in hospitals and, with SAIDA's help, send them to doctors.

We have also made initial plans for forming links with health professionals in hospitals in specifically disadvantaged areas. Our plan is to identify parents or women with TS who would form the nucleus of satellite TS groups. We have learnt that people cannot travel the distances in Jo'burg to maintain one unified group. We hope eventually to assist a number of such satellite groups to form, under our umbrella. With the help of SAIDA, we hope to assist members of these satellite groups with support counseling training.

We have finally succeeded in creating a website, which is linked to that of SAIDA on the Wits site. Our TS booklet has also been scanned and is available as a pdf document on the site. I believe we must also be unique in the world in that our website contains Turner information in eight different languages. This has taken a considerable amount of time, but we were reliant on the goodwill of SAIDA and Wits staff.

With the help of SAIDA, we brought the information from the last international conference to the attention of health professionals in South Africa. They have finally also managed to send our report-back to the members who requested it.

We have continued with our work of providing help and advice to those in need. We seem to have increasing numbers of queries from the parents of newly diagnosed babies, or from women who are pregnant with Turner babies. This is a good sign. Not only does it mean there seems to be a greater tendency to diagnose our girls early, but it also means the genetic department and health professionals are referring these people to us in greater numbers.

We are able to give these parents the information and advice they crave, since we have kept up with the most current research and methods of treatment around Turner Syndrome. Since we are trained as counsellors, we are also able to counsel parents and to give pregnant mothers enough objective information to allow them to make informed decisions regarding their pregnancies.

Since the medical faculty at Wits University is being restructured, we were unable to do our usual job of addressing third year medical students in order to give them the facts about Turner Syndrome in an interactive way. However, this will resume as soon as the genetics department has worked out how to include us in the new curriculum.

We supported SAIDA's fundraising dance and we have continued our liaison with the Community Chest.

We are struggling to raise money, and would desperately love a member to volunteer to assist us in this function, even on a commission basis. Our dream is to raise enough money to employ someone a couple of mornings a week to work with our membership, attract keen new members, and consolidate the membership we have. While we have continued, this year, to send out timely and accurate accounts - generated on our computer by Samara Dall - our existing membership list still needs a great deal of work. We have, however, continued to expand our membership base and Samara has continued in her attempts to

work on the existing list. Thank you Sam. I know how hard you work for us.

Many of our members have moved without telling us their change of address or telephone number. We appeal to members to let us know when they move, so that they can continue to receive our mail.

I appeal to our successful young women with TS to retain contact with the group, even if you feel you don't need its support right now. In fact, please wrest control from my grasp. That's the way we should be going. I promise I won't mind. We need new blood if we are to take on new projects and fulfill our objectives. Why don't you teens make contact via the website and form a teen group, to share objectives, hopes and problems?

Liz Zylstra and Samara Dall has ably produced our newsletter this year. It has been filled with information, news and views. The role of the Newsletter is vital, since it is sometimes the only link that our far-flung members have with the group. As usual, I'd like to make special mention of Hazel Stein (Ucko), who finally had to move to Australia to escape the work of the group, Lawrence and Jennifer Gobetz who spent hours of their time and expended much expertise on us, Perle Greenberg, who took great care of our financial affairs, Tamara and Neil, Danie, Liz Zylstra and Samara Dall, always delightful and extremely hard-working members.

JO-ANNE RICHARDS
CHAIRMAN