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THE SYDNEY UNIVERSITY CHILDREN'S COCHLEAR IMPLANT PROJECT.

I am extremely concerned about the future of the Children's Project. We neither have salaries in place for the staff, nor a proper facility in which to work. My own salary is only guaranteed until the end of December and there are no alternative funds in place for its continuation after that date. Although I have worked without a salary for several periods in the past, I am extremely loath to be put in that position again.

Over the past 3 years, I have put an enormous amount of effort into getting outstanding results with the first group of children. I have certainly established the efficacy of the device with the current users, and have also created a great deal of hope for potential candidates. However, the project will not be able to continue unless we obtain substantial corporate and public funding. This would enable us to employ a team of professionals and to obtain a proper facility for the work.

Every week I have visitors to the storeroom at Chatswood who want to observe the habilitation program. The Melbourne team visited for 3 days recently, the Auckland group will be here for a week in November, the Adelaide group will also be here in November, and there is a speech pathologist from Denmark who wants to see the work. As you can imagine, it is extremely difficult having people observe in the tiny room at Chatswood. The children are always put off by visitors. However, I accept them in these poor conditions because it is a way of creating support.

Rosalie Yaremko is a tremendous asset to the project. She is very competent in her work and is extremely nice with the children and parents. I like her as a person, and enjoy having her as a colleague to work with. However, I am highly embarrassed that she has nowhere to work. At present she is seeing the

preschoolers in the resource room at Chatswood School. The big problem, however, is that we never know when someone wants to come and find materials, or when a group needs to use the room. She can be right in the middle of a 1 hour session with a child when she is interrupted and has to move. Mostly, she just goes into the corridor and tries to continue out there with people going past causing further interruptions.

We are both working in terrible conditions. The present group of implantees are not getting a fair deal, and we certainly can't accept any more candidates until the problems are sorted out. However, I do not think that the project should be limited by the resources that are currently available. We should be expanding those resources and building a strong program for the children in N.S.W. We need proper facilities in which to work, and a strong habilitation team to develop the program. Its strength will depend on the professionals we attract to the work. Good results are only possible with good professionals.

At present, there are 2 teenagers, 11 school-aged children and 7 preschoolers in the project. But that is just the tip of the iceberg. I am sure that more candidates will come forward as the months go by because people are talking about the work. Graeme Clark recommended the latest candidate.

THE HABILITATION TEAM.

I think we should now aim at building a team of professionals to carry out the habilitation program. The members of this team should be employed in full-time career positions, both to carry out the habilitation in this research phase of the project, and to train other professionals for the clinical work in the future. Their work will provide leadership and will establish high expectations in the field.

This team initially should include myself, Rosalie Yaremko, Sylvia Romanik, and an audiologist as the core group. I will outline their roles in the following section:

- Gaye Nicholls. Co-ordinate the re/habilitation program, design and carry out research studies, assess candidates, program implants, teach programming and habilitation techniques to other clinicians, present lectures, publish papers.

- Rosalie Yaremko. Conduct habilitation programs with preschoolers, carry out research studies, train other clinicians.

- Sylvia Romanik. Conduct rehabilitation programs with

school-aged candidates, carry out research studies, train other clinicians.

- An audiologist. Program implants, carry out the assessment protocol with all the candidates.

However, I think we should also aim to expand that team as more implant candidates are accepted into the program. The core group should begin to train professionals in other centres, such as the Shepherd Centre, St. Gabriel's and the new Auditory-Verbal School, but we will need additional team members to set up regional centres in the future.

A FACILITY FOR THE PRE-SCHOOL PROGRAM.

The habilitation for the pre-school group involves weekly sessions. Rosalie works both with the child and parent to set goals for the parent to follow-up during the week. These goals include listening, speech and language targets.

We now have 7 preschoolers in the program, and we could accept another 5. We should employ another clinician to assist Rosalie once we have more than 12 children in the program. In the long term, I think that we will need one preschool clinician to work with children in our own facility, and another one to train professionals in other centres.

We need a facility in which the pre-school program can be based. There needs to be a) habilitation rooms with observation windows, b) a programming room with an observation window, c) a sound-proof room for the audiologist, d) an office, e) storerooms and, f) an audio-visual room.

Options for the Preschool Facility.

1. The Yenibis Deafness Research Centre.

This centre would be ideal. However, if its role is not decided within week, I think we should find a suitable alternative.

2. A Rented House.

I am now looking for a rental property close to the university for temporary accomodation. Rosalie and I saw a very pleasant house in Holmwood St., Newtown that will be available in the next 2 weeks. It is the home of a person who will be overseas until the middle of next year. It has been renovated

and is in a quiet tree-lined street. I would like you to have a look at it because I think it would be a nice place for children to come to. I didn't like the house at 197 Missenden Road at all.

3. A Suite of Rooms in the Queen Elizabeth Rehabilitation Centre.

In the long term, we need to apply for space in the Q E 11 Rehab Centre, or other accomodation at Royal Prince Alfred. Although this may take some time to procure, it will be well worth the effort in the long run.

4. Accomodation in the University of Sydney.

If it is impossible to find space at RPA, the next option would be the university.

5. Appeal to a donor such as Larry Adler to buy a house for the project.

6. Lobby the Housing Department for a subsidised rental property.

7. Buy a house ourselves from money obtained for the E.A.R. Foundation.

A FACILITY FOR THE SCHOOL CHILDREN'S PROGRAM.

The habilitation for the school-aged group varies in accordance with the children's language and verbal development. Children who are just beginning their language development require daily sessions of at least an hour in duration. Children who have more sophisticated language and are integrated into their own local schools require weekly sessions.

If Sylvia Romanik is employed on the project she could work with 4 children who need daily habilitation sessions, and 4 children who need weekly sessions.

At present, the work with school-aged children is being conducted in the book storeroom at Chatswood Infants School. We need to consult with the Principal at Chatswood to ensure that this room can be used in the short term. However, it is quite inadequate for the long term.

I think we should establish this centre as a model program for implantees in the school system. We should lobby the

Education Department to set up habilitation and observation rooms attached to the Hearing Support Unit at Chatswood. In the past year, the Hearing Support Unit has attracted a great deal of attention for the excellent auditory-verbal program they have developed.

OPTIONS FOR OBTAINING FUNDS.

I think it is essential that we obtain both corporate and public funding. We need corporate sponsorship to provide on-going funds for the research, and we need public funds to establish the clinical program. These funds should cover salaries, clinical facilities and administrative costs.

1. A Private Fund Raiser.

I was extremely disappointed to learn that the Vice Chancellor was cogitating over our application to employ Barbara Bridges as a fund raiser. It is inconceivable that we would be able to obtain the necessary funds ourselves. We were extremely fortunate to obtain Barbara Bridges interest in the project and should pursue this option most vigorously.

I think that the Children's Implant Project would be most attractive to corporate sponsors, and that given the go ahead, Barbara Bridges would be able to raise a substantial amount of money. Professor Gibson mentioned the figure of \$2 million. I think that we need enough money to cover the immediate costs, but we also need to invest a substantial amount of money for the on-going research needs.

2. Public Funds.

We should prepare a detailed submission to the Health Department for funds to cover the implant centre's staffing, administrative and equipment needs. However, the main thrust should be to obtain salaries. These are the most difficult items to obtain from private sources as they need to be established in perpetuity.

We should also prepare a detailed submission to the Education Department. I know that Loretta Giorcelli is opposed to the work, but she must not be able to hamper or stop us. I think we should present our case in writing first through the appropriate channels. We should also plan for a delegation to see the Minister and leave our submission with him. AND, IF THAT FAILS, WE SHOULD GO TO THE MEDIA. My contact in the Premier's Department, Leone Healey, said that the Premier's 'minders' are very sensitive to media issues, and that a media blow-up is

probably our best bet.

In the submission to the Education Department, we need to:

1. Outline the project. Discuss the export strength of the implant and the interest that the Sydney children's project has attracted within Australia and overseas.

2. Discuss the opposition to the work within the Education Department. (NB. We have Loretta on tape saying that the work is not successful).

3. Outline the needs:

- Staff:

a) Full-time teachers of the deaf who are highly skilled with auditory-verbal teaching techniques. These teachers will provide the initial intensive habilitation for children who receive implants.

b) Itinerant teachers of the deaf to support children in mainstream classes. These teachers also need to be highly skilled with auditory-verbal techniques.

- Auditory-verbal hearing support units.

- A training program for teachers of the deaf who will be working with children who receive cochlear implants.

4. Outline the cost effectiveness of this project. We are preparing children for mainstream education. We would also need to discuss our preparedness to provide some of the funding ourselves. However, we need to stress that we could not possibly hope to raise ALL the money.

I will look forward to working on the plans for the project and request that I am included in all meetings in which the habilitation program is being discussed.

Regards,



Gaye Heather Nicholls Ph.D.

Research Fellow

Sydney University Children's Cochlear Implant Project