THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Nadia Letts, 2002 Churchill Fellow

To investigate the latest developments in paediatric Myoelectric Prosthetic Programs and attend the Myoelectric Controls Symposium ‘2002.

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Signed: _________________________ Dated: _________________________

Nadia Letts
29th November 2002
## INDEX

1. Introduction and Acknowledgments 3
2. Executive Summary 4
3. Fellowship Program 6
4. Background Information 7
5. Paediatric Prosthetic Program Overview
   - 5.1 The Children’s Hospital at Westmead, Australia 8
   - 5.2 Bloorview MacMillan Children’s Centre 11
   - 5.3 Rehabilitation Institute of Chicago 14
   - 5.4 Shriners Hospital for Children (Chicago Unit) 16
   - 5.5 Shriners Hospital for Children (Los Angeles Unit) 18
6. Conclusions and Recommendations
   - 6.1 Comparison of Limb Deficiency and Amputee Clinic Services 21
     - 6.1.1 Limb Deficiency / Amputee Clinic structures 21
     - 6.1.2 Funding sources available for providing prosthetic limbs 22
     - 6.1.3 Indications and ages for prescription of prostheses 23
     - 6.1.4 Types of prosthetic componentry used 24
     - 6.1.5 Assessment, training and evaluation resources 24
     - 6.1.6 Prosthetic training techniques 24
   - 6.2 Future Needs for Paediatric Prosthetic Management in Australia 25
   - 6.3 Dissemination of Findings 25
7. Reference List 26
1. **INTRODUCTION AND ACKNOWLEDGMENTS**

This report outlines my 2002 Churchill Fellowship to investigate the latest developments in paediatric Myoelectric Prosthetic Programs, through undertaking a study tour of renowned centres of excellence in prosthetic training of children with limb deficiencies, and attending the Myoelectric Controls Symposium 2002 at the University of New Brunswick.

Myoelectric prostheses have become an internationally accepted standard in the treatment of paediatric upper limb deficiencies. The number of children with such disabilities is small, and as such there is only a small number of experienced therapists in this area in Australia and indeed internationally. The provision of myoelectric prostheses is expensive, and it is therefore important that children with upper limb deficiencies are provided with, and trained in the use of myoelectric prostheses along international standards. This ensures that prostheses are prescribed responsibly, and that children gain optimal function from their prosthetic arm/s.

This Fellowship has provided the opportunity to compare the services provided by The Children’s Hospital at Westmead with those of internationally renowned centres. Specific areas of study included:

- Limb Deficiency / Amputee Clinic structures
- Funding sources available for providing prosthetic limbs
- Indications and ages for prescription of prostheses
- Types of prosthetic componentry used
- Assessment, training and evaluation resources
- Prosthetic training techniques

The ability to undertake this Fellowship would not have been possible without the support and assistance of the following people and organisations.

First and foremost, I would like to thank the Winston Churchill Memorial Trust for providing me this opportunity, and for recognising the needs of Australian children with disabilities to access services of an international standard.

I would like to thank the Variety Club of New South Wales for their ongoing generosity and financial support of the Myoelectric Hand Program at The Children’s Hospital at Westmead.

I would like to thank the medical and allied health staff at the paediatric facilities I visited, for their assistance in arranging the logistics of the Fellowship, for their warm welcomes, for sharing their wealth of knowledge, and mostly, for sharing their enthusiasm for their work. In particular, I would like to thank:

- Sheila Hubbard, Anne Martin and Shane Glasford - Bloorview MacMillan Children’s Centre
- Dr Deborah Spira and Jamee Heelan - Rehabilitation Institute of Chicago
- Camille O’Reilly - Northwestern University
- Dr Jeff Ackman, Cathy Schroeder and Leah Bent - Shriner’s Hospital for Children, Chicago
- Dr Yoshio Setoguci, Joanna Patton and Joanne Shida - Shriner’s Hospital for Children Los Angeles

I would like to thank the staff of the Limb Deficiency Clinic and Occupational Therapy Departments at The Children’s Hospital at Westmead for their support of the Fellowship, from initial planning and application through to my return home.

Finally, I would like to thank the children and families of the Limb Deficiency Clinic at The Children’s Hospital at Westmead. Their courage, determination and strength provide the inspiration behind our work.

Nadia Letts
Churchill Fellow 2002
2. EXECUTIVE SUMMARY

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Project Description:

To undertake a study tour of paediatric Myoelectric Prosthetic Programs in Canada and the USA, and to attend the Myoelectric Controls Symposium ‘2002.

Fellowship Highlights:

1. Attendance at the Myoelectric Controls Symposium ‘2002, held at The Institute of Biomedical Engineering, University of New Brunswick. This was a 5-day training workshop and conference, involving participants from Australia, Canada, USA, UK, Japan, The Netherlands, Germany, Austria and Sweden.

2. The opportunity to attend Limb Deficiency/Amputee Clinics at a number of Canadian and USA hospitals, whose programs and therapists are internationally recognised for their expertise in the prosthetic management of children. These included:
   - Bloorview MacMillan Children’s Centre, Toronto Canada.
   - Rehabilitation Institute of Chicago, Chicago USA
   - Northwestern University, Chicago USA
   - Shriner’s Hospital for Children, Chicago USA
   - Shriner’s Hospital for Children Los Angeles, Los Angeles USA

Findings:

The use of myoelectric prostheses has become an international standard in the treatment of paediatric upper limb deficiencies, in addition to the more conventional passive, recreational and body powered prostheses. Myoelectric prostheses should be prescribed for children where indicated as a part of their overall prosthetic management. The Children’s Hospital at Westmead was seen to be providing similar and comparable clinical services to those seen in Canada and the USA. However the centre visits, observation of clinical practice, and the opportunity to discuss optimal service provision has raised avenues for improvement in Australian services.

This includes:
1. Review of services provided at The Children’s Hospital at Westmead
2. Gathering of statistical data regarding paediatric limb deficiency and prosthetic use.
3. The use of prosthetic-specific outcome measures and evaluation tools.
4. Training opportunities for allied health professionals in Australia.
5. Opportunities for allied health professionals to attend international conferences training courses.
7. Review of funding sources, as it is important that funding policies reflect current paediatric prosthetic management practice.

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Churchill Fellow 2002
Proposed Dissemination of Information:

Presentation of Fellowship findings to:

1. Limb Deficiency Team at The Children’s Hospital at Westmead
2. Occupational Therapy Department at The Children’s Hospital at Westmead
3. Occupational Therapists involved in Upper Limb Prosthetics in New South Wales

Plans for formally presenting findings to therapists at other paediatric Myoelectric Programs (Melbourne, Adelaide and Perth) are to be investigated, although this is difficult due to geographical separation.

Training Courses:

1. Invited to present on paediatric prosthetic management at the ‘Clinical Management of Upper Limb Amputees’ course to be held at Prince Henry Hospital/University of New South Wales, July 2003

Plans for further training courses are currently being investigated. These include:

1. Lectures at undergraduate Occupational Therapy and Prosthetic training schools in paediatric prosthetic management
2. Training workshops for Upper Limb Prosthetic Training, in conjunction with therapists from adult services

Conference Presentations

Planned abstracts to be submitted for the following conferences:
1. ISPO Australia Annual Scientific Meeting – Melbourne, 2003
2. Occupational Therapy Australia – New South Wales State Conference 2004
3. FELLOWSHIP PROGRAM

Toronto, Canada 14 – 16th August 2002
Bloorview MacMillan Children’s Centre

Fredericton, Canada 19th – 23rd August 2002
Institute of Biomedical Engineering, The University of New Brunswick
- Workshop – “Practical Training Approaches to Powered Upper Extremity Prosthetics”
- Conference – “Myoelectric Controls Symposium 2002”

Chicago, United States of America 3rd – 6th September 2002
Rehabilitation Institute Of Chicago
Department of Prosthetics and Orthotics, Northwestern University
Shriners Hospital for Children

Los Angeles, United States of America 10th September 2002
Child Amputee Prosthetic Project (CAPP), Shriners Hospital for Children
4. BACKGROUND INFORMATION

The Limb Deficiency Clinic at The Children’s Hospital at Westmead services approximately 400 children from throughout New South Wales and regional areas of Australia. These are children that are either born with a congenital limb deficiency, or have an acquired amputation through injury, illness or disease.

“The estimated prevalence of limb deficiencies in the general population is 1 in 1,000 persons, and over 10% of these persons are children. Congenital limb loss accounts for up to 70% of amputations in children with the majority being below-elbow limb losses. Approximately 1 child in 4,200 is born with a congenital upper-limb deficiency” (cited in Wright, Hubbard, Jutai and Naumann, 2001).

The Limb Deficiency Clinic provides a multidisciplinary treatment team that includes Clinical Genetics, Rehabilitation Medicine, Occupational Therapy, Physiotherapy, Social Work and Prosthetic services. The Clinic provides a wide range of services that aim to provide support and counselling for families to accept their child’s deficiency, and to assist the child to develop the necessary skills required for independence in the everyday activities of play, self care and school. A key service that the clinic provides is the prescription, fitting and training of prosthetic limbs.

For children with upper limb deficiencies, the prosthetic options available are:

- Passive prosthesis
- Recreational prosthesis
- Body-powered prosthesis
- Externally powered prosthesis (including myoelectric prosthetic fittings)

A myoelectric prosthesis is an artificial arm where the electromyographic signal generated by a contracting muscle is detected by surface electrodes and used to control the opening and closing of an electrically powered hand. The myoelectric arm is often preferred by parents and children over the body powered prosthesis as it has a more cosmetic appearance and does not require external harnessing. For many families, the cosmesis offered by the myoelectric prosthesis is an important part of accepting their child’s disability (Wright et al, 2001)

In conjunction with the Variety Club of New South Wales, the Limb Deficiency Clinic provides a myoelectric prosthetic program for children with congenital deficiencies or amputations of the upper limb. The Myoelectric Hand Program was established in 1984 with the generous support of the Variety Club of New South Wales, and was the first such clinic to be established in Australia. Additional myoelectric prosthetic programs now operate at the respective Children’s Hospitals in Melbourne, Adelaide and Perth.
5. **PAEDIATRIC PROSTHETIC PROGRAM OVERVIEW**

5.1. **The Children’s Hospital at Westmead**  
**Myoelectric Hand Program**

**Staff**  
Medical Staff - Dr Adrienne Epps/Dr Jenny Ault (Rehabilitation Specialists)  
Therapy & Allied Health - Nadia Letts (Occupational Therapist)  
Sarah McConnell (Social Worker)  
Biomedical Engineer - Tony Easterbrook  
Prosthetists - Rudi Doller (Appliance & Limb Centre)  
David Hughes (Premier Prosthetics)

**Clinic Structure**  
- Clinic is held 2x month. All children, not just those suitable for fitting with myoelectric prostheses, attend this clinic.  
- A meeting is held prior to the clinic to review the medical background of each child.  
- All members of the clinic team see the child concurrently.

**Clinic Numbers**  
- Approximately 400 children attend the clinic. This includes all children with limb deficiencies (both upper and lower limb), and those managed with and without prostheses.  
- The current number of children using a myoelectric prosthesis is 18, with a further 7 infants due to be fitted with prostheses in the next 2 years.

**Funding Source**  
The provision of prosthetic limbs in New South Wales is funded by the government based Artificial Limb Scheme of NSW. This covers the cost of conventional prostheses such as the passive, recreational and body-powered limbs. It does not provide for the provision of myoelectric prostheses.

The myoelectric hand program is funded by the Variety Club of NSW Children’s Charity. This funding supplies all equipment for the limb bank, including consumables such as gloves and batteries. The NSW Artificial Limb Scheme covers the cost of fabrication of the prosthesis. There is no cost to the family. The current cost of a myoelectric prosthetic fitting is $12,000, with an additional cost of $4,500 for subsequent re-fittings. Due to growth, children may require refitting of their prosthesis at 6 month to 2-year intervals.

The program is available for children up to the age of 18 years, at which time the transition to adult services occurs. At present, funding for myoelectric prosthesis by the Variety Club is confined to The Children’s Hospital at Westmead, and is therefore unavailable once children reach the age of 18.

**Prosthesis Prescribed**  
- Passive  
- Recreational  
- Body-powered  
- Myoelectric

**Number of Prostheses Offered:**  
This is dependent on the needs of the child. In general, the child has a primary prosthesis (ie a myoelectric or body powered limb), and one or two secondary prosthesis (ie a passive hand and a recreational prosthesis).
Prosthetic Services
The prosthetists are private practitioners, with all fabrication and fitting of prostheses conducted off site. Both prosthetists attend the clinic.

Prosthetic Componentry

Body Powered
- Mechanical Hand
- Split hook
- CAPP

There is a decreasing trend in prescribing body powered prostheses, with the majority of children being fitted with a myoelectric prosthesis from age 3 onwards.

Myoelectric
- Ottobock

Myoelectric components are held in a ‘limb bank’, enable componentry to be recycled and shared between children as the prostheses are outgrown.

Ages of Prosthetic Fitting – General Guidelines

<table>
<thead>
<tr>
<th>Age</th>
<th>Prosthesis Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 months</td>
<td>Passive prosthesis (e.g. crawling mitt)</td>
</tr>
<tr>
<td>2.5 years +</td>
<td>Body powered prosthesis</td>
</tr>
<tr>
<td></td>
<td>Mechanical hand</td>
</tr>
<tr>
<td></td>
<td>CAPP</td>
</tr>
<tr>
<td></td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td></td>
<td>Single site control</td>
</tr>
<tr>
<td>4 years +</td>
<td>Body powered prosthesis</td>
</tr>
<tr>
<td></td>
<td>Mechanical hand</td>
</tr>
<tr>
<td></td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td></td>
<td>Dual site control</td>
</tr>
</tbody>
</table>

Selection Criteria for Myoelectric Prosthetic Fitting
- Unilateral mid forearm length below elbow (transradial) amputation or deficiency
- Within normal development (cognitive, motor, social)
- Established wearing pattern of a body powered or passive prosthesis

Additional criteria:
- Stable social situation
- Geographical location – this would not preclude a child from the program, but families need to be able to travel to Sydney for assessment, training and fabrication of the prosthesis.

Prosthetic Training and Review

Children are seen for muscle site selection prior to attending casting of the prosthesis, and may attend for muscle site training sessions prior to receiving the completed prosthesis if a new fitting or changing from a single site to dual site control system. Training is provided at the final checkout stage of the prosthesis, with additional follow up depending on the family’s access to the hospital. This would generally consist of 2 – 3 training sessions.

Children attend clinic for review on a yearly basis, with more frequent appointments in their younger years. Children must attend for a clinic review to have a new prosthetic prescription.
Occupational Therapist Role
- Prosthetic Assessment and Training
- Developmental and Fine Motor Assessments
- School Liaison (school transition, modifications, equipment, prosthetic use)
- Handwriting and Computer Access
- Equipment prescription (self care, mobility)
- ADL skills training
- Parent/Child psychosocial groups

Assessments
- Peabody Fine Motor Scale – developmental assessment
5.2 Bloorview MacMillan Children’s Centre
Myoelectric Program

**Staff:**
- Clinic Coordinator - Sheila Hubbard (Occupational Therapist/Physiotherapist)
- Medical Staff - Dr William Cole (Orthopaedic Surgeon)
- Therapy & Allied Health - Sheila Hubbard (OT/PT)
  Anne Martin (Occupational Therapist)
  Mary Huggins (Physiotherapist)
  Gert Montgomery (Social Work)
- Prosthetists -
  Winfried Heim (Certified Prosthetist)
  Shane Glasford (Certified Prosthetist)
  Kevin Martin (Prosthetic Technician)
  Sol Wierzb (Prosthetic Technician)
  Ian Whatmough (Prosthetic Technician)

**Clinic Structure**
- Clinic is held 1x afternoon per month
- Staffed by Social Worker, Occupational Therapist/Physiotherapist, Prosthetist and Surgeon.
- Clinic is held primarily to see new patients and those needing surgical opinions. Each child/family is seen first by the Social Worker to identify and address family needs and concerns. This information is then passed on to the OT/PT and prosthetist, who discuss the prosthetic options available with the family. The final appointment is then held with the surgeon, generally to review surgical options.
- Referrals accepted from throughout Ontario. Some referrals also received from overseas.

**Clinic numbers**
- 300 active prosthetic clients - all clients are using either a myoelectric, body-powered or passive upper limb prosthesis
- approx 2/3 children, 1/3 adult

**Funding Source**
Government funding is available through the “Assistive Devices Program”. The funding received pays for a percentage of the cost of the limb, and the exact amount of funding received is dependant on the level of deficiency the child has (ie transradial deficiency vs transhumeral deficiency). The funding will pay for the primary prosthesis only. This may be a passive, body-powered or myoelectric limb, depending on the needs of the child and the prescription determined by the clinic team. The program will not pay for a recreational prosthesis.

Other options available to supplement this funding, and to provide a secondary prosthesis (often a recreational limb) include:
- Health Insurance
- CHAMPS (children’s amputee support organisation aligned with the War Amputations Association of Canada)

Due to government and health insurance funding requirements, componentry is unable to be shared between clients.

**Prostheses Prescribed**
- Passive
- Body-powered
- Myoelectric
Number of Prostheses Offered
- 1x Primary Prosthesis (ie myoelectric prosthesis, funded by the “Assistive Devices Program”)
- 1x Secondary (ie Recreational Prosthesis, alternative source of funding required such as health insurance or CHAMPS)

Prosthetic Services
The prosthetists/prosthetic technicians work within the myoelectrics department, with all services provided in house. All assessments, fittings, final checkouts are conducted with both the OT and Prosthetist present.

Prosthetic Componentry

Hands
The clinic uses a combination of VASI (Variety Ability Systems Inc.) and Ottobock components.

The VASI hands are available in 3 sizes, these being 0-3, 2-6 and 5-9. The sizes are based on age increments. Hand sizes 0-3 and 2-6 are routinely used until early primary school age, as they are an appropriate size and shape in comparison to the sound limb on a young child. The VASI hand is found to have a superior grip to the younger Ottobock hands. The Ottobock hands tend to be used for older children and adolescents in preference to the VASI 5-9 hand, as it has a more cosmetic appeal and is a lighter weight. This is a particular consideration for those children with short residual limbs.

The cost comparison between the VASI myoelectric hand and the Ottobock myoelectric hand is as follows

<table>
<thead>
<tr>
<th></th>
<th>VASI</th>
<th>Ottobock</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost CDN</td>
<td>$4,000 CDN</td>
<td>$6,000 CDN</td>
</tr>
</tbody>
</table>

Infant fittings can be fitted with a parental access switch. This enables the hand to be opened by the parent/therapist, to help facilitate the initial training process and use of the prosthesis.

Wrist units
The clinic prescribes the OMNI wrist for use in conjunction with the VASI hands. This mechanical wrist unit provides a greater amount of wrist movement, allowing for radial/ulnar deviation, flexion/extension and pronation/supination. The OMNI wrist is also used with recreational prostheses and activities, including fittings to a bike and ice hockey stick.

Wrist rotation units are not routinely prescribed due to their contribution to the increase in weight of the prosthesis, and the increased time need to change between prosthetic functions. They are however considered for the bilateral amputee, or if a child was unable to manually turn the wrist with the opposite hand.

L’il E-Z Feed hand
This is an infant sized mechanical hand. The hand is designed so that the thumb can be manually opened with a spring close, thus enabling the hand to hold small toys and objects. These objects can be easily fed into the prosthetic hand with the child’s sound hand.

Whilst this is not being used at Bloorview MacMillan Children’s Centre (as infants and young children have funding available to be fitted with a myoelectric prosthesis) it could be used as a step between the initial fitting of a passive crawling prosthesis and the first myoelectric prosthesis fitting at preschool age.
Ages of Prosthetic Fitting - General Guidelines

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Prosthetic Type and Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 months +</td>
<td>Passive prosthesis (e.g., crawling mitt)</td>
</tr>
<tr>
<td>10 months +</td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td></td>
<td>Single Site Control</td>
</tr>
<tr>
<td></td>
<td>Voluntary Opening</td>
</tr>
<tr>
<td></td>
<td>Parental Access Switch</td>
</tr>
<tr>
<td>3 years +</td>
<td>Myoelectric Prosthesis (Preschool/Kindergarten)</td>
</tr>
<tr>
<td>(Preschool/Kindergarten)</td>
<td>Dual Site Control</td>
</tr>
</tbody>
</table>

Selection Criteria for Myoelectric Prosthetic Fitting
All patients are assessed for the suitability of prosthesis. Where effective control of the prosthesis is queried, a mock-up will be fabricated to further assess suitability.

Prosthetic Training and Review
Children are generally seen 3 x per year when they require a new prosthetic fitting. This includes appointments for casting, socket checks and the final fitting. Follow-up is provided via telephone calls.

Occupational Therapist Role
- Prosthetic Assessment (in conjunction with prosthetist) and liaison with families in regards to suitable prosthetic options
- Developmental Assessments
- School Liaison
- Non-prosthetic management (e.g., equipment, ADL skills training)

Most occupational Therapy contact is provided on a consultancy basis, with phone consultations where possible.

Assessments Used
- PUFI (Prosthetic Upper-Extremity Functional Index) - outcome measure assessment, based on functional use of the prosthesis and client satisfaction
- UNB Test of Prosthetic Function – conducted at final fitting for each new prosthesis
- Goal Attainment Scale
- AIMS (Alberta Infant Motor Scale) - Developmental assessment 0 – 18 months

The PUFI is now available for clinical trial. The Children’s Hospital at Westmead has enrolled in the international study, and will be collaborating with the Bloorview MacMillan Children’s Centre to further refine its use and provide international data on the satisfaction and use of myoelectric prostheses.
5.3 Rehabilitation Institute of Chicago
Variety Club Children’s Amputee Program

Staff:
Clinic Coordinator - Jamee Heelan (Occupational Therapist)
Medical Staff - Dr Deborah Spira (Rehabilitation Specialist)

Clinic Structure
- Clinic is held 1x per month
- Multidisciplinary clinic
  Orthopaedic surgeon
  Rehabilitation Specialist
  Occupational Therapist
  Prosthetist
- Clinic is held to review prosthesis fit and to maintain contact with families.
- Initial appointments to discuss prosthetic management are made separate to any medical appointments. These appointments involve an initial consultation with the OT and Prosthetist to discuss the benefits of all types of prostheses at length.

Clinic numbers
- Approx 280 clients (includes all UL, LL, bilateral and multiple limb deficiencies)

Funding Source
Options for prosthetic funding are as follows:
1. Health Insurance – amount of funding available depends upon the individual insurance company. The may pay for all or part of the prosthesis, with a part payment required to be made by some families.
2. Self Funded
3. Peoples Aid – government assistance scheme for low income families, however must pass an asset means test for consideration
4. Donated Funds – a limited amount of donated funds is available for specific client groups (ie amputation resulted as a consequence of cancer)

Prostheses Prescribed
- Passive
- Body-powered
- Myoelectric

Fittings are provided for partial hand, transradial, transhumeral and shoulder disarticulation deficiency/amputation levels.

Number of Prostheses Offered
This is dependent on approval from Health Insurance provider. In order to gain approval, the need for an additional limb needs to be separate from the primary limb (ie a recreational limb). Families are required to pay for additional limbs if insurance funding is not available.

Prosthetic Services
The prosthetists/prosthetic technicians work within the hospital, with all services provided in house. All assessments, fittings, final checkouts are conducted with both the OT and Prosthetist present.
Prosthetic Componentry

Hands
Prosthetists have a preference for VASI

Wrist/Elbow units
Electric powered wrist and elbow units are not used for paediatric clients.

Ages of Prosthetic Fitting - General Guidelines

<table>
<thead>
<tr>
<th>Age</th>
<th>Prosthetic Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 months</td>
<td>Passive prosthesis (eg crawling mitt)</td>
</tr>
<tr>
<td></td>
<td>Must have sitting balance 5 – 10s</td>
</tr>
<tr>
<td>12 months +</td>
<td>Passive prosthesis</td>
</tr>
<tr>
<td></td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td></td>
<td>Single Site Control</td>
</tr>
<tr>
<td></td>
<td>Voluntary Opening</td>
</tr>
<tr>
<td>3.5 years +</td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td></td>
<td>Dual Site Control</td>
</tr>
</tbody>
</table>

Prosthetic Training and Review

1. New active prosthetic fitting
   - Prosthetic fabrication – seen at appointments for casting, check out of socket, and then final fitting.
   - Prosthetic training – provided with 2 – 5 follow up training appointments, dependant upon insurance funds, parent’s access to the hospital and so forth

2. General clinic review and follow up
   - Attend clinic review every 4 months until 3 years of age
   - Attend clinic review every 6 months from 3 to 5 years of age
   - Maintain contact with family every 6 months from 5 years of age. Clinic visits may not be required, however attempts are made to keep contact by telephone

Occupational Therapist Role

- Prosthetic Assessment (in conjunction with prosthetist), liaison with families in regards to suitable prosthetic options and Prosthetic Training
- School Visits/School Liaison

School visits are offered when the child enters Kindergarten, Yr 7/8, or transfers to a new school. Funding provides for a ‘School Kit’, which includes amputee dolls, children’s books and examples of prostheses. The talks involve the showing of the amputee doll and discussion on differences, limb deficiency, prostheses follows. The duration of the talk is approximately 1 to 1.5 hours. Donated trust funds provide a kit for the school of the amputee dolls and children’s books for ongoing use.

- Parent/Child Groups

Open playgroups are held at the hospital for all families, with older children and parents undertaking the role of mentor for newer families. In addition, horse riding and sports training camps are held for older children. Groups are held approximately every 2 months.

Assessment

- Assisted in the development of the OPUS Children’s Scale – however not presently using. Limited by time constraints
- Hawaii Early Learning Profile (HELP) – Developmental Assessment

Nadia Letts
Churchill Fellow 2002
5.4 Shriners Hospital for Children (Chicago Unit)

Staff:
- Medical Staff - Dr Jeffrey Ackman
- Therapy & Allied Health - Cathy Schroeder (Clinical Nurse Coordinator), Leah Bent (Occupational Therapist)
- Prosthetist - Jim Kaiser (Certified Prosthetist), Harold Schoene (Certified Prosthetist)

Clinic Structure
- Clinic is held 1x week
- Staffed by Medical Specialist, Occupational Therapist, Physiotherapist and Prosthetist
- Services the surrounding 5 states

Funding Source
The Shriners Hospital is a charity-funded organisation. There is no cost to the family in attending the hospital, or in the provision of prosthetic limbs. Where possible, insurance companies are billed if the family has health insurance. This assists with reducing the costs for the Shriners Hospital. As the service is funded by charity, a limb bank can be used to recycle prosthetic components between children.

Prostheses Prescribed
- Passive
- Body-powered
- Myoelectric

Number of Prostheses Offered
The Shriner’s Hospital is able to provide as many prosthesis as required by the child. This generally equates to a primary prosthesis (body powered or myoelectric) and a recreational prosthesis.

Prosthetic Services
Prosthetic services are provided by private companies located external to the hospital, however the prosthetists attend the clinic. All fabrication and fitting of prostheses conducted off site. Where possible, insurance companies are billed if the family has health insurance. This assists with reducing the costs for the Shriners Hospital.

Prosthetic Componentry

Body Powered
- Li’I E-Z Feed Hand
- Mechanical Hand
- Split hook
- Adept

Myoelectric
- VASI
- Ottobock
Ages of Prosthetic Fitting - General Guidelines

- 6 months + Passive prosthesis (eg crawling mitt)
  - L’il E-Z Feed Hand
- 2.5 to 3 years + Body powered prosthesis
  - ‘Adept’ hand
  - Split hook
  - Cables may/may not be attached
- 4 years + Body powered prosthesis
  - Cables attached
- 5 to 6 years + Body powered prosthesis
  - Myoelectric prosthesis

Occupational Therapist Role
- Prosthetic assessment and liaison with families in regards to suitable prosthetic options, in conjunction with medical staff and prosthetist
- Informal developmental and functional ADL assessment
- Non-prosthetic management (ie ADL equipment and skills training)
- Home program for prosthetic training

Assessments
- Participating in trial of OPUS Children's Scale
5.5  Shriners Hospital for Children (Los Angeles Unit)
Child Amputee Prosthetic Program

Staff:
Medical Staff -  Dr Yoshio Setoguci (Head of Department)
          Dr John Lawrence (Hand Surgeon)
          Dr Hugh Watts (Orthopaedic Surgeon)
Therapy & Allied Health -  Joanna Patton (Occupational Therapist)
          Joanne Shida (Occupational Therapist)
          Leigh Gegenburg (Social Work)
          Chris Caron (Physiotherapist)
          Natalie Wise-Aguilar (Physiotherapist)
          Margaret Haruki (Physiotherapist)
Prosthetists -   Jeff Honma (Certified Prosthetist)
                   Anthony Ellis (Certified Prosthetist)
                   David Craft (Certified Prosthetist)
                   Michael Carter (Certified Prosthetist)
                   David Freire (Certified Prosthetist)
                   Robert Lee (Prosthetic Technician)
                   Denis Jordan (Prosthetic Technician)
                   Martin Mendoza (Prosthetic Technician)

Clinic Structure
• Clinic is held 3x per week, however all staff members are available on a full time basis and are therefore able to see children as needed.
• Clinic appointments are first held with the Occupational Therapist and Prosthetist to identify prosthetic issues. A case management meeting is held following this appointment to discuss management approaches and progress. The child and family are then invited into the meeting.
• Initial appointments to discuss prosthetic management involve an initial consultation with the OT to discuss the benefits of all types of prostheses at length.
• Families are provided with a letter from the clinic outlining the expectations of attendance and review if accepted into the prosthetic program
• Referrals are accepted from Southern California and surrounding states, including Mexico. Charity organisations arrange for children from overseas (ie African nations, Russia) to attend for prosthetic fitting.

Clinic numbers
• Approximately 500 children, with an even ratio of upper and lower limb deficiencies.
• The majority of these children are considered active users of their prosthesis

Funding Source
The Shriners Hospital is a charity-funded organisation. There is no cost to the family in attending the hospital, or in the provision of prosthetic limbs. Prosthetic services are provided by in house prosthetists. Where possible, insurance companies are billed if the family has health insurance. This assists with reducing the costs for the Shriners Hospital.

For children attending the clinic from outside of the USA (other than Mexico), they must be self-funding for transport and accommodation. Prosthetic fitting and training is provided free of charge.

The prosthetic program occasionally receives grants and donations, enabling them to provide a small number of myoelectric prosthesis. Overall, funds limit the prescription of prostheses to body-powered designs.
Prosthetic Myoelectric Prosthetic Programs

Prostheses Prescribed
- Passive
- Body-powered
- Myoelectric (limited number of myoelectric prostheses offered)

Number of Prostheses Offered
Children are provided with only one prosthesis – namely a body powered, myoelectric or a passive mitt for infants. Recreational and cosmetic prostheses are not provided for older children.

Prosthetic Services
The prosthetists/prosthetic technicians work within the myoelectrics department, with all services provided in house. All assessments, fittings, final checkouts are conducted with both the OT and Prosthetist present.

Prosthetic Componentry

Body Powered
- Li’l E-Z Feed Hand
- Mechanical Hand
- Split hook
- CAPP

Myoelectric
- VASI 0 – 3 and 2-6
- Ottobock 6 3/4 +
The VASI hands are used for younger children as it has a superior grip to the Ottobock 2000. The Ottobock hands are used for older children for their cosmetic appeal.

CAPP
The CAPP terminal device was developed by the Child Amputee Prosthetic Program and the University of California – Los Angeles (UCLA). The CAPP is used predominantly with preschool aged children. Whilst it is not as effective at holding cylindrical objects, it is useful in holding flat objects such as paper.

Ages of Prosthetic Fitting - General Guidelines

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Passive Prosthesis</th>
<th>Body Powered Prosthesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infants (6 months +)</td>
<td>Crawling hand</td>
<td>CAPP</td>
</tr>
<tr>
<td></td>
<td>Foam Hand</td>
<td>Mechanical Hand</td>
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<tr>
<td></td>
<td>L’il E-Z Feed hand</td>
<td>Myoelectric prosthesis</td>
</tr>
<tr>
<td>Toddlers (2.5 to 3 years +)</td>
<td>Body powered prosthesis</td>
<td>Selected children only</td>
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<tr>
<td></td>
<td></td>
<td>Single site control</td>
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<tr>
<td>School aged (5 years +)</td>
<td>Body powered prosthesis</td>
<td>Mechanical Hand</td>
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<td></td>
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<td>Split hook</td>
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<td></td>
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<td>Myoelectric prosthesis</td>
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<td>Selected children only</td>
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<td>Dual site control</td>
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</tbody>
</table>
Children and families are instructed that the prosthesis (passive, body powered or myoelectric) are to be worn full time for a 6 month period to establish a consistent pattern of wear and acceptance of the prosthesis.

**Selection criteria for myoelectric prostheses**
Due to funding restraints, children are carefully assessed for their suitability to use a myoelectric prosthesis. Children are selected for using a myoelectric prosthesis based on the following:
- Establishment of solid prosthetic wearing patterns
- Strong family commitment to attendance at clinic appointments
- Proximity to the hospital for regular review and maintenance of the myoelectric prosthesis

**Prosthetic Design**
Supra condylar suspension is not often used, rather a biceps/triceps cuff is used to suspend the prosthesis. This is particularly used with infants. In addition, the infants prosthesis have an axilla strap to further help with suspension, and to enable the child to adjust to using a body powered prosthesis at a later date.

**Prosthetic Training and Review**
Children are generally seen 3 x per year when they require a new prosthetic fitting. This includes appointments for casting, socket checks and the final fitting.

Ongoing training is provided as required. This is provided by community therapists, early intervention services or at the Shriner’s Hospital.

All children attending the clinic are seen for review every 8 months. If using a prosthesis, the child is reviewed every 4 months. Children must be seen a minimum of every 8 months to be considered an active client, and therefore able to access prosthetic services. Families are provided with a letter from the clinic outlining expected appointment and review schedules.

**Occupational Therapist Role**
- Prosthetic assessment and training
- Non-prosthetic management (ie equipment, ADL skills training)
- Training courses for community based therapists in paediatric prosthetic training

**Assessments**
Currently using a variety of standardised assessments as part of research study, including:
- PedsQL – Paediatric Quality of Life Inventory
- PUFI – Prosthetic Upper Extremity Functional Index
- CAPP - PSI
- U-Bet – Functional prosthetic use assessment, including items from the UNB test of prosthetic function
- DOTS-R - temperament survey
- PODCI
6. CONCLUSIONS AND RECOMMENDATIONS

6.1 Comparison of Limb Deficiency and Amputee Clinic Services

6.1.1 Clinic Structure

The number of children attending the various amputee clinics for prosthetic management was larger than that seen at The Children’s Hospital at Westmead, as would be expected with the population size of North America compared to that of Australia.

All of the clinics visited had a strong multidisciplinary focus, with representation by medical, allied health and prosthetic staff. The clinics were held with a strong emphasis on the prothetic management of the child, rather than on medical and developmental needs. Whilst these were addressed as required, initial appointments to discuss prothetic options were made separate to any medical appointments. The focus of these initial consultations was to demonstrate and discuss the benefits of all types of prostheses at length. In the majority of clinics, this was conducted by the occupational therapist and prosthetist.

Bloorview MacMillan Children’s Centre, the Rehabilitation Institute of Chicago and The Shriners Hospital (Los Angeles Unit) have prosthetic staff working in-house, thereby allowing close collaboration with occupational therapists during the assessment, casting and fitting process. The benefits of such collaboration were seen to be the ease and convenience for families in providing one centre for prescription, fabrication, training and follow up; immediate access to repairs of the prosthesis for problems identified during training and review appointments; and the development of strong professional relationships leading to opportunities for research, education and product development. The Shriners Hospital (Chicago Unit) have private practitioners working in close proximity to the hospital and who attend each clinic, as does The Children’s Hospital at Westmead.

The Child Amputee Prosthetic Project at The Shriner’s Hospital (Los Angeles Unit) also provides a letter to families that clearly outlines the clinic procedures, and the expectations of the family in attending review appointments.

Recommendations for The Children’s Hospital at Westmead

1. Update of protocols for the clinic attendance, review requirements and criteria for inclusion in the upper limb prosthetics programs
2. Provision of letter or contract to families to outline expectations of attendance and review
3. Establishment of an ‘Upper Limb Prosthetics’ clinic 2 times per year, with formal case reviews and planning meetings to be held between the medical staff, occupational therapist and prosthetist.
4. Revision and update of the Limb Deficiency database. This will assist in keeping statistical data on the number of children either using or potentially being able to use an upper limb prosthesis, helping to maintain contact with families, assist with planning for future services and to aid in future research.
6.1.2 Funding Sources

The availability of prostheses, and in particular the myoelectric prostheses, is very dependant on funding. Funding schemes varied considerably, and are dependent on government programs and initiatives, health insurance availability and/or charity organisations. The source of funding was also determined if myoelectric components could be held in a ‘limb bank’ and shared between children, thereby reducing program costs.

The Bloorview MacMillan Centre is able to supply myoelectric prostheses to children from a very early age due to the availability of funds from the Canadian government’s ‘Assistive Devices Program’, with supplementary funding from the CHAMPS organisation and through private health insurance. Financial assistance with providing the myoelectric prostheses is available for both adults and children. Due to government and health insurance funding requirements, componentry is unable to be shared between clients.

The provision of myoelectric prostheses for children with non-compensable limb deficiencies in the USA requires private funding through health insurance or through the generosity of philanthropic organisations such as the Shriners and the Variety Club. The level of funding available is a significant factor in determining the availability of a myoelectric prosthesis. Programs such as CAPP program at the Shriners Hospital in Los Angeles prescribe a very limited number of myoelectric prostheses, with the majority of children being fitted with a body-powered prosthesis. The Shriners Hospitals are able to use a ‘limb bank’ scheme.

The Myoelectric Hand Program at The Children’s Hospital at Westmead is funded by annual donation from the Variety Club of New South Wales, with the Artificial Limb Scheme covering the cost of fabrication of the prosthesis. There is no cost to the family if the child has a Health Care Card, and the program operates with a ‘limb bank’. The program is available for children up to the age of 18 years, at which time the transition to adult services and hospitals occurs. At present, funding for myoelectric prosthesis by the Variety Club is confined to The Children’s Hospital at Westmead, and is therefore unavailable once children reach the age of 18. The Artificial Limb Scheme is able to provide for body powered prostheses, but does not supply myoelectric prostheses for adults or children.

Recommendations for The Children’s Hospital at Westmead:

1. Whilst the Variety Club has generously provided funding for the Myoelectric Hand Program since 1984, this is reviewed on a yearly basis and the ongoing availability of such funds should not be taken for granted. In addition, the program at The Children’s Hospital at Westmead is limited to children under the age of 18, and myoelectric prostheses are not offered to adults under the Artificial Limb Scheme. The need for permanent funding sources and availability of myoelectric prostheses for children once they have reached the age of 18 years needs to addressed.
6.1.3 Indications and ages for prescription of prostheses

The age of myoelectric prosthetic fitting had a large variance. The Bloorview MacMillan Centre has a strong emphasis on early fitting, with infants being fitted with a myoelectric from the ages of 10 months onwards. The premise behind the early fitting is that the child is able to incorporate the use of the prosthesis into their body scheme during the natural period of motor development. Furthermore, it is deemed to be effective in developing consistent wearing patterns, as “young childhood appears to be a crucial time for affecting a child’s willingness to use a prosthesis” (Wright et al, 2001). The availability of funding also enables these children to be fitted at an early age.

Myoelectric prostheses at the Rehabilitation Institute of Chicago and the Shriner’s Hospitals (Chicago and Los Angeles Units) were generally prescribed from the ages of 3 onwards. Prior to this age, children were fitted with passive and body powered prostheses. These centres continue to provide body powered prostheses for older children where clinically indicated or if funds for myoelectric prostheses are unavailable. It is important to note that Bloorview MacMillan Children’s Centre also provide body-powered prostheses where clinically indicated.

All prosthetic prescription is based upon clinical reasoning and judgement, with all centres prescribing the prosthetic limb indicated for the individual child. Due to funding restraints at the Child Amputee Prosthetic Project, limited numbers of children can be provided with a myoelectric limb. Assessment of their suitability to use a myoelectric prosthesis is based upon the establishment of solid prosthetic wearing patterns, strong family commitment to attendance at clinic appointments and proximity to the hospital for regular review and maintenance of the prostheses. A similar selection criterion exists for children attending The Children’s Hospital at Westmead.

Recommendations for The Children’s Hospital at Westmead

1. Continued prescription of all types of prostheses as clinically indicated including passive, body powered, recreational and myoelectric limbs.
2. Due to the limited availability of funds, the prescription of myoelectric prostheses may need to continue to be for children aged 3 years and over. However, the benefits of early fittings as seen at Bloorview MacMillan Children’s Centre should continue to be monitored and implemented into practice when financially achievable.
6.1.4 Types of Prosthetic Componentry Used

All centres used a combination of the VASI and Ottobock myoelectric hands, with the VASI hand being used for the toddler and preschooler fittings and Ottobock used for school aged children and adolescents. The Omni wrist unit was used extensively at Bloorview MacMillan Centre. Body powered and passive componentry included the crawling mitt, L’il E-Z feed hand, adept, split hook and CAPP terminal devices.

Wrist rotation units were not routinely prescribed at any clinic due to their contribution to the increase in weight of the prosthesis, and the increased time need to change between prosthetic functions. They are however considered for the bilateral amputee, or if a child was unable to manually turn the wrist with the opposite hand.

Recommendations for The Children’s Hospital at Westmead

1. Trial the use of the OMNI wrist in conjunction with a myoelectric fitting.
2. Trial the use of the L’il E-Z Feed Hand as a step fitting between the initial fitting of a passive crawling prosthesis and the first myoelectric prostheses at age 3 years. If this is deemed suitable, an application to the Artificial Limb Scheme will be made to have it included on the prescription list for prosthetic components.

6.1.5 Assessment, training and evaluation resources

The use of outcome measures is becoming increasingly important in health service provision. Prosthetic-specific outcome measure and evaluation tools for children with limb deficiencies have been developed, and include the Prosthetic Upper Extremity Functional Index (PUFI) and the Orthotics and Prosthetics User Survey (OPUS).

The UNB Test of Prosthetic Function was identified as standardised assessment designed for use specifically with children aged 2-13 with a unilateral upper extremity prosthesis. Developmental assessments were used by all occupational therapists, and included the Alberta Infant Motor Scale and the Hawaii Early Learning Profile. The Child Amputee Prosthetic Project was using a large number of assessments as part of a research project, including the Paediatric Quality of Life Inventory (PedsQL), PUFJ, CAPP-PSI, U-Bet, DOTS-R and PODCI.

Recommendations for The Children’s Hospital at Westmead:

1. The clinic at The Children’s Hospital at Westmead has enrolled in an international trial of the PUTFI, and will be collaborating with the Bloorview MacMillan Children’s Centre to further refine its use and provide international data on the satisfaction and use of myoelectric prostheses.
2. Further investigation is to be undertaken into the use of the OPUS.

6.1.6 Prosthetic Training Techniques

A workshop entitled “Practical Training Approaches to Powered Upper Extremity Prosthetics” was completed at the Institute of Biomedical Engineering, The University of New Brunswick, as part of the Fellowship. Further training techniques were observed at all centres visited during the course of the Fellowship. Course notes from the workshop and training manuals will be kept in the Limb Deficiency Clinic at The Children’s Hospital at Westmead, and are available on request.
6.2 Future Needs for Paediatric Prosthetic Management in Australia

The visits to the prosthetic centres, observation of clinic practice, and the opportunity to discuss optimal service provision has raised avenues for improvement in Australian services and for support and training of associated professionals.

This includes:

1. Gathering of statistical data regarding paediatric limb deficiency and prosthetic use, so as to be able to clearly identify the needs of this group and assist with funding applications and substantiate avenues of research.

2. The use of prosthetic-specific outcome measure and evaluation tools for children with limb deficiencies, such as the Prosthetic Upper Extremity Functional Index (PUFI) and the Orthotics and Prosthetics User Survey (OPUS). The Children’s Hospital at Westmead has since enrolled in an international trial of the PUF1, with further investigation to be undertaken into the use of the OPUS.

3. Development of ongoing training opportunities for allied health professionals in paediatric prosthetic training techniques within Australia.

4. Opportunities and funding is required for allied health professionals to attend national and international conferences and training courses in paediatric prosthetic management to maintain levels of knowledge in training principles and product development, and to develop an international network of colleagues. This includes conferences held by groups such as International Society for Prosthetists and Orthotists and the Association of Children’s Prosthetic-Orthotic Clinics.

5. Establishment of formal links between myoelectric programs in Australia to develop a national and unified treatment approaches to paediatric prosthetic management.

6. Review of funding sources. It is important that funding policies, such as the Artificial Limb Scheme, reflect current paediatric prosthetic management practice.

6.3 Dissemination of Information

The findings of this Fellowship have been presented to the Limb Deficiency Clinic and Occupational Therapy Departments at The Children’s Hospital at Westmead, with a further presentation to be made to Occupational Therapists involved in Upper Limb Prosthetics in NSW. Formal presentations to other paediatric myoelectric programs in Melbourne, Adelaide and Perth are to be investigated, although this is difficult due to geographical separation. Presentations and meetings at professional conferences may be the most appropriate solution. Abstracts will be submitted to present at the ISPO Australia Annual Scientific Meeting, and Occupational Therapy Australia conferences.

Ongoing training and education was identified as a need. I have been invited to present on paediatric prosthetic management at a ‘Clinical Management of Upper Limb Amputees’ course to be held at Prince Henry Hospital/University of New South Wales, July 2003. I am also investigating the opportunity to present lectures at undergraduate Occupational Therapy and Prosthetic training schools in paediatric prosthetic management, and to present occupational therapy training workshops for Upper Limb Prosthetic Training, in conjunction with therapists from adult services.

Nadia Letts
Churchill Fellow 2002
7. REFERENCE LIST