



## the *featherweight* club

### **Strategic Plan 2009**

#### **Background**

The *Featherweight* Club (FWC) seeks to provide support to families who have or have had a baby in Special Care, in particular within the Neonatal Services Unit at Mercy Hospital for Women (MHW). FWC seeks to raise awareness of the particular needs of these babies and their families both within the hospital environment and the broader community.

FWC provides an avenue for parents to communicate their requirements and suggestions. We recognise that parents' main areas of concern while their baby is in hospital include but are not limited to:

- Information about their babies' care;
- Communication with medical staff;
- Breastfeeding support; and
- Car parking and accommodation so they can be with their baby.

FWC endeavours to advocate for or provide programs that will deliver the practical support required by families to alleviate these and other areas of concern.

FWC seeks to support those families whose babies leave hospital by endeavouring to ensure they are equipped with the education and information they need to help them effectively care for their own babies in the short and long term.

#### **Goals**

FWC's goals include to:

1. Promote and enhance communication and positive relationships between MHW and families whose babies are admitted to the Special Care Nursery and the community
2. Assist in the practical and emotional support of families through the implementation of programs aimed at supporting families whose babies are in Special Care, transitioning from hospital to home and at home
3. Advocate for a collaborative, multidisciplinary approach to long-term care to ensure continuity and optimal outcomes for families
4. Encourage utilisation of education and research to enhance delivery of evidence-based care for these babies and their families

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5. Promote education for families and the community, empowering families to become confident and independent in providing care and advocating for the ongoing needs of their babies
6. Represent the parent community on committees and other appropriate bodies relevant to providing support to babies and their families and raising awareness of their needs.

### **FWC Structure**

FWC is a volunteer organisation attached to the Neonatal Services Unit at Mercy Hospital for Women. FWC is not an independent legal entity. It is not a traditional hospital volunteer auxiliary. Effectively, FWC most closely represents a consumer representative committee but it requires funding to implement projects.

FWC has an established committee of volunteers that meet regularly.

### **Functions / Objectives**

The major functions of FWC Volunteer Committee are to:

1. Provide parent perspectives of current concerns
2. Coordinate Working Groups to plan and implement programs and projects on behalf of FWC
3. Ensure the programs and projects put forward and developed fit in with the main areas of concern identified by parents and will help to fulfil FWC's goals and objectives of supporting Special Care babies and their families
4. Put forward proposals for joint projects between the FWC and Mercy Health

### **Programs and Activities**

FWC's programs and activities are designed to meet our goals of supporting parents who have a baby in special care as well as to provide a communication link and an outlet for parents to contribute to improving their own journey and those of the parents who will follow them.

FWC's programs and activities can be divided into 4 main categories, each of which is intrinsically linked:

1. Education / Information

The information available to parents who have a baby in special care is limited. It has improved considerably over recent years but there remains room for further improvement. What is available primarily consists of basic information regarding the hospital and nursery environment and suggestions as to how parents can interact with their baby while it is in hospital.



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FWC believes there is a need for the systematic and timely provision of accurate and relevant information, particularly for parents. This information needs to be delivered at appropriate times both while the baby is in hospital and, for children born extremely prematurely, afterwards, as particular milestones are reached. Removing some of the uncertainty or even just providing reassurance about the normal spectrum of growth and development, particularly for babies born extremely prematurely, has a positive impact on relieving the stress and concern of parents and families who have the ongoing responsibility of caring for these children.

There is almost nothing available, particularly in an Australian context, relating to:

- extended families
- managing home and family life while living with a baby who is hospitalised for an extended period of time
- how to prepare for baby coming home
- what happens once baby is home
- nurturing the mother's physical and mental health
- growth and development of extremely premature babies and what parents should be aware of and expect at various stages
- the translation of the latest research into everyday language that consumers can understand, including the focus of "how does this condition / developmental issue affect my family's everyday life?" or "what does this look like in my child?"

Education and information about the ongoing needs of children born prematurely or sick and their families should not only be directed to parents and families. Other people involved in the ongoing care of these children also need to be far better informed than they are currently. This includes Maternal and Child Health Nurses, GP's and school teachers.

FWC's information strategies play a key role in opening a 2-way communication channel between FWC, parents and other relevant parties. This is important if we are to fulfil our desired role as consumer representative / advocate for babies in special care and their families.

### **2. Peer Support**

FWC believes that a quality Peer Support Program should be just one of the resources available to families and, in particular, mothers, to ensure their good mental health and well-being during the period of their baby's hospitalisation and in the transition from hospital to home and beyond.

Not only are these mothers at greater risk of developing postnatal depression but post traumatic stress syndrome, which may not manifest itself until much further down the track, is now increasingly being identified as a real concern. This is not yet well-recognised by all relevant parties.

### **3. Practical Support**

Having a baby in hospital can be a significant burden on otherwise functioning families, both emotionally and financially. It stretches reserves of physical and



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emotional endurance and, in various different ways, can be a costly experience, financially and otherwise.

Due to limited resources, FWC currently undertakes only a token effort at providing some level of practical support for families. We would like to be able to achieve more. Ideally, this would include the capacity to:

- help the SCN purchase capital equipment or other items that would otherwise be low on the priority list but are necessary to maintain the standards of care we expect; and
- assist families with extraordinary needs that result from their baby's residence in the SCN (those that would otherwise "fall through the cracks" left by existing services).

#### **4. Consumer Representation and Advocacy**

Representing the views of parents and families and advocating for their needs and those of their babies and children is a critical component of FWC's activities. We currently have FWC volunteers sitting as consumer representatives on a number of relevant committees both within Mercy Hospital for Women and the Department of Human Services, Victoria. There is scope to expand this role.

FWC's prime objective is to ensure that it is in the best possible position to deliver relevant, tangible support to families whose infants are in / have been in Special Care. FWC does not desire to be the organisation delivering these services but to facilitate their introduction and availability in areas where they do not already exist or are limited.

Our relationship with the Mercy Health Group and, specifically, the Neonatal Services Unit at Mercy Hospital for Women provides the FWC with a unique point of difference to any other similar group of which we are currently aware. This offers the opportunity to make a real and tangible difference to the experience families have whilst their infant is in special care at Mercy Hospital for Women. We believe this can only enhance MHW's reputation for providing compassionate care.

There are two areas that FWC has identified as requiring significant improvement:

- **Growth and Development:** Links closely to the provision of information and education for relevant parties (i.e., parents, GP's and teachers), particularly for children born extremely prematurely. At present, there are ad hoc programs, implemented to varying degrees by individual hospitals and based on particular research interests. There is no comprehensive, cohesive program that focuses on the needs of the children and their families and on how their developmental differences might impact on daily life at various ages and stages. There is no capacity for families to provide feedback about issues that may arise over time with their children.



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- **Transitional Care:** The transition from hospital to home, particularly for babies who have been medium to long term residents in hospital and require a more intensive level of care than average new-borns is most often a very difficult and isolating experience for new mothers and the support available has changed very little over recent years.

We believe there is opportunity to progress towards a different type of care for both babies and mothers during this transitional phase. It would appear to fit in with the Victorian Government's goal of "Keeping Mothers and Babies Together" and ensuring limited hospital resources are utilised in the optimum manner. There is an opportunity to work with the Early Parenting Centres, such as Mercy Health's own O'Connell Family Centre, in developing transitional arrangements that will focus on parent support and education.

FWC aims to pursue the improvement in these areas via Mercy Hospital for Women and on a higher level within the Neonatal industry as a whole.

**5. Fundraising**

Fundraising has a two-fold purpose for FWC. Firstly, it is to generate the funds required to support planned projects. Secondly, as a support group we aim to provide an outlet for parents and families to express their gratitude and thanks to those who helped care for their baby and to share their experience with parents travelling the same path subsequently. While we understand the concept of philanthropy and developing professional and corporate relationships, it is also important that we maintain a channel to facilitate contributions from our grassroots supporters and the families we are endeavouring to help. However, we need to manage this in such a way as to minimise the disruption and distraction this can have on our main tasks and objectives.

<b>The Featherweight Club's Programs and Activities</b>		
<b>Program / Activity</b>	<b>Current</b>	<b>Future Plans</b>
Education / Information	<p><u>Expressions (FWC Newsletter):</u></p> <p>Currently published quarterly for distribution to all families who have had a baby admitted to the SCN at MHW. Next mail out will be to more than 3500 families mainly across Victoria.</p> <p>The Newsletter content can be readily adjusted to fit in with the other communications and publications planned for the future (refer next column).</p>	<p>FWC is aiming to develop an Australian resource centre dedicated to parenting premature babies and children.</p> <p>Focus will be on translating academic research and best practice into practical, everyday strategies for families and carers of special care babies and children and other parties closely involved with the child's early development.</p> <p><u>FACT Sheets / Information Booklets:</u></p>

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	<p><u>Website:</u></p> <p>Currently being redesigned. Plan is to build content via FACT Sheets and Information Booklets (refer Future Plans).</p> <p>Separate professional section??</p> <p><u>E-newsletters:</u></p> <p>To be used as a regular communication tool with supporters / interested parties and as first point of release for newly published FACT sheets</p>	<p>Plan is to publish regular FACT Sheets. FACT Sheets may be targeted at:</p> <ul style="list-style-type: none"> <li>- parents and families</li> <li>- Maternal and Child Health Nurses</li> <li>- GP's</li> <li>- school teachers</li> <li>- Other relevant parties.</li> </ul> <p>They will be prepared / editorially overviewed by relevant, professionally qualified people within Mercy Health and the professions and based on topical information relevant to:</p> <ol style="list-style-type: none"> <li>1. babies in special care</li> <li>2. needs of families</li> <li>3. growth &amp; development issues of premature children</li> <li>4. services available in local communities, especially regional areas</li> </ol> <p><u>Information Sessions</u></p> <p>FWC has previously conducted a number of Family Information Sessions. Guest speakers at the Information sessions were appropriate professionals from Mercy Health. Examples include Chief Psychiatrist, VISP Hearing Screening, Speech Pathologist, etc. These sessions were attended by an average of 40 – 50 families.</p> <p>We would like to develop a series of information sessions, aimed at our different target groups, and that will complement the FACT sheets.</p> <p><u>Staff Seminars</u></p> <p>There is often a gap in staff</p>

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		<p>knowledge and understanding of the issues families face when their baby is in hospital. There is scope to build programs to fill these gaps, particularly in terms of contributing to the training of new staff.</p>
Peer Support Program	<p><u>Hospital:</u> Currently working with MHW to develop a comprehensive Peer Support Program to include:</p> <ul style="list-style-type: none"> <li>- direct referrals to FWC</li> <li>- "morning tea" events</li> <li>- Nursery visiting</li> <li>- antenatal visits</li> </ul> <p>Program will require:</p> <ul style="list-style-type: none"> <li>- volunteer recruitment, screening and training</li> <li>- volunteer support</li> <li>- ongoing administration</li> </ul> <p>This could be a model to be promoted to other similar neonatal units.</p> <p><u>Premie Playgroup:</u> Currently running two monthly playgroups in metro Melbourne.</p> <p>FWC's Premie Playgroup was one of the first of its kind. There are now alternatives available in various locations, some of which have obtained Gov't funding due to socio-economic status of area.</p> <p>Premie Playgroup is an important part of the care that should be provided and available to families during the transition from hospital to home and beyond.</p>	<p>FWC's focus is not to be a service provider but to provide information to families who need it.</p> <p>Under consideration:</p> <ul style="list-style-type: none"> <li>- Development of support information / guidelines for professionals / individuals wanting to establish Premie Playgroups / working with families who have had a baby in special care</li> <li>- Continuing to advocate / lobby for more formalised support system for families bringing extremely premature baby home</li> <li>- Premie Playgroup @ Boroondara to cease in early 2010 unless new volunteer facilitator can be found to replace / assist Merran Taylor.</li> <li>- Focus will be on collating and publishing information about all relevant playgroups operating in Victoria. Links in with FWC becoming premium source of information and education for premie parents within Victoria.</li> </ul>

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	FWC will never be in a position to be able to provide a service that is accessible to most families. Should FWC be aiming to provide this service?	
Practical Support	<p><u>Special Occasion Gifts:</u> FWC currently provides gifts for babies in SCN during Easter, Mother's Day, Father's Day and Christmas</p> <p><u>Craft:</u> FWC developing a "manual" of patterns for items required in the nurseries at MHW. Aim is to reduce quantity of useless items by distributing approved patterns.</p>	<p>We would like to:</p> <ul style="list-style-type: none"> <li>- provide "Welcome Packs" including emergency essentials for mothers admitted at short notice</li> </ul>
Consumer Representation / Advocacy	<p>Members of FWC Volunteer Committee are represented on:</p> <ul style="list-style-type: none"> <li>- FWC Mercy Liaison Committee</li> <li>- Mercy Breastmilk Bank Steering Committee</li> <li>- Neonatal Services Advisory Committee (DHS, Vic).</li> </ul>	<p>FWC plans to allocate resources to advocate for better programs relating to:</p> <ul style="list-style-type: none"> <li>- Growth &amp; Development and follow up, particularly in relation to extreme prems and the provision of relevant educational and informational materials to key stakeholders (parents, doctors, teachers, etc)</li> <li>- Transitional Care</li> </ul>
Fundraising	<p><u>Birthday List:</u> Ongoing program aimed at encouraging families to become regular financial donors</p> <p>Has potential to expand and develop, particularly in relation to online fundraising activities and personal fundraising web-pages.</p>	<p>We aim to:</p> <p>Formalise FWC's role as the fundraising arm of MHW's Neonatal Services Unit.</p> <p>The introduction of FWC Newsletter, mailed to all families who have a baby admitted and funded by FWC, created an immediate "conflict" for</p>

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	<p><u>Merchandise Sales:</u> Mainly a marketing tool. Cooler bags are useful for transportation of EBM for mothers with babies in SCN.</p> <p>Options to expand relatively limited due to the lack of a suitable sales outlet and no online sales capacity at present.</p>	<p>potential donors.</p> <p>Formalising FWC's role as fundraising arm allows for a streamlined, effective and concerted approach and provides an outlet for publicity and promotion of fundraising efforts. It allows for FWC and the SCN to work more closely together in building a recognisable "face" that can be shown to the public and internally as one united cause for fund-raising purposes.</p>
Capital Works	Completion of 2 <sup>nd</sup> Floor Terrace – main expense is shade cover.	No future plans.