



## “PEP Talk”

Health professionals and parents working together to help families successfully live with the challenges of a bleeding disorder.

- Anne Jackson - Clinical Practice Consultant – Haemophilia  
Women’s and Children’s Hospital South Australia**
- Sharon Hawkins - Senior Social Worker – Haemophilia  
Haemophilia Centre of Western Australia**
- Cheryl Ellis - Parent Facilitator, Western Australia**

- Parents Empowering Parents (PEP) course was conceptualised by Danna Merritt from the Children's Hospital Detroit
- Co-authored by Sandra Joseph, child and family therapist, Detroit
- Consultation with parents of children with inherited bleeding disorders and HTC staff.

## Method of teaching PEP course

- PowerPoint slides
- Parent's Manual
- Facilitators Manual
- Different teaching techniques:
  - lecture
  - role play
  - facilitation of discussion
  - written exercises



- Parents Empowering Parents course in Perth, Western Australia 28<sup>th</sup>, 29<sup>th</sup> and 30<sup>th</sup> August, 2009
- Delivered by a team:
  - Anne Jackson, Haemophilia Nurse, SA
  - Sharon Hawkins, Haemophilia Social Worker, WA
  - Cheryl Ellis, parent facilitator, WA

## Need to collaborate

- unavailable trained staff in each state
- Small numbers of parents of children in target group

## Target

- Parents of children from SA and WA attended
- Parents of children aged 0 – 11 years of age
- Identify future parent facilitators for PEP course

- HFA support to run PEP
- PEP ten sessions normally taught over 10 weeks
- Adapted to 3 day course for WA/SA collaboration of PEP course due to:
  - distance primarily
  - concerns about parents ability to commit to 10 weeks







P A R E N T S  
E M P O W E R I N G  
P A R E N T S

## PEP Course sessions:

1. The Basics of Bleeding Disorders
2. Child Development
3. Compassionate Discipline
4. Fine-Tuning Behaviour Management
5. Understanding your World View
6. How thoughts and Feelings Affect Parenting
7. Building Self-Esteem
8. Understanding the Process of Communication
9. Refining Communication Skills and Conflict Resolution
10. Parenting Styles

- Benefits



- Peer support
- Team approach

- Relationship building  
between parents and  
HTC staff







PARENTS  
EMPOWERING  
PARENTS

# Public Speaking!

## The PEP Programme

- targets families living with bleeding disorders
- Has ideas & strategies that can be used by all families
- Aims to make families aware of the basics of bleeding disorders, ensure a gradual & age-appropriate handing over of bleeding disorder management from parent to child & helping parents to communicate more effectively with their children and partners

## Session 5 :Understanding Your Unique World View

### Guiding questions:

- Introducing yourself & any history of bleeding disorder
- Cultural & spiritual beliefs
- Socialisation
- Life experiences
- Financial experiences as a child

## What I gained out of PEP

- My parenting style (Inconsistent!)
- How to set up an “action plan” with my husband to enable our children to become caring, capable & resilient
- To try to demonstrate good behaviours for my children to model
- How my personal views and experiences affect how I function as a person, parent & partner
- Public Speaking experience

# Role of the Nurse

- Collaborative support of the social worker who leads the team
- To provide specific bleeding disorder information
  - Genetics
  - Diagnosis
  - Treatment
- Haemophilia A & B , Von Willebrand Disorder

## Identified:

- the impact of a bleeding disorder on lifestyle and parenting
- Appropriate learning at developmental ages
  - Transfer of knowledge, education
  - Involvement in decision making
  - Sharing of responsibility
  - Teaching self treatment and care
- Understanding why parents hold on to aspects of care
  - Responsibility/guilt
  - Overcoming hurdles



# PEP –WA Evaluation

- Questionnaire
- Attended and completed by 7 parents
  - 2 Fathers & 5 Mothers
  - 5 from WA & 2 from SA
  - 15 children
- 9 children with a bleeding disorder
  - No inhibitors
  - 3 families with children on prophylaxis

# Evaluation



- 2.5 -14 years experience of parenting
- Ethnicity
  - 3 Australian
  - 1 Burmese/English
  - 1 Greek/Australian
  - 1 Maori
- Average age of parents
  - 36.4 years



- All participants strongly agreed or agreed:
  - Course met its goal
  - Material was useful
- PEP program rated valuable by 6 participants and not too valuable by 1 participant
- Rated well organised by all participants

- Length and content rated just right and covered just enough by 6 participants
- All participants indicated extremely likely or very likely to make changes in how they parent
- Responses to how likely they were to encourage their whole family to apply PEP to their lives
  - 6 extremely likely/very likely
  - 1 somewhat likely

- 3 parents extremely likely or very likely to be peer trainers
- 6 participants would recommend the course to other parents



All participants agreed or strongly agreed they:

- Can identify the type of interaction with their child that is most difficult to handle
- Are more aware of the impact of communication on their children and relationships
- Can identify various types of communication barriers
- Have a deeper understanding of how children develop and the impact on communication in their family



- Have a deeper understanding of Haemophilia/VWD and what part it plays in communicating and disciplining their children
- Have gained skills in dealing more effectively with their feelings when parenting
- Identify techniques to be more effective in dealing with difficult situations

6 out of 7 parents agreed or strongly agreed and 1 parent disagreed that they:

- Have a deeper understanding of what haemophilia or Von Willebrand Disorder has had on them
- Have gained skills in dealing more effectively with their feelings when parenting
- Feel more confident that they can build more collaborative relationships with their child's treatment team

# Suggestions for Improvement

- Covered too little "Maybe extend age to 13 to help pre teen parents"
- "A larger opportunity for parents to interact out of course time..... without facilitators. Parents are able to communicate on a parent level."
- "Having parents return in 4-5 years to see how their experience may have impacted on their communication, feelings & situation that they dealt with.."

“I find that getting together with other parents of children with haemophilia so valuable. I would like to be involved in presenting a session if this is appropriate. .. I will enjoy sharing lots of good ideas with my family....”



# Future

- Integrate the feedback into the planning for future programs
  - more opportunity for peer only support
- Seek funding for South Australian program in 2010
- Parents identified to have role in facilitation
  - Provide further training and support
- Collaboration into the future
  - Train more health professionals in each state

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