

# HFNZ Women's Programme

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**In recent years there has been increased recognition of the unique issues faced by women with inherited bleeding disorders.**



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## Women bleed too



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## History

- HFNZ have employed a range of approaches to increase awareness and understanding of these unique issues.
- 1998 – vWD support group initiated
- 2004 & 2005- Publicity
- 2005 -1<sup>st</sup> Young Women's Workshop Weekend
- 2008 -Mother's and Daughter's Weekend
- 2008 Survey of Female Membership



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## Survey of Female Members - 2008

- Tried different forms of targeted education workshops:
  - Young Women (very successful)
  - Mothers and Daughters (less uptake)
- HFNZ surveyed their female membership to better understand their needs.

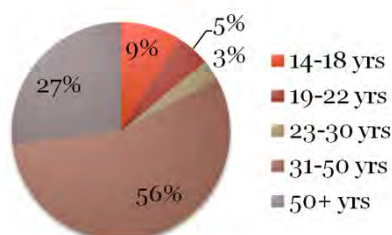


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## Women's Survey Results

- 77 responses (26.4%)
- 65% would attend a women's workshop
  - Most of those that said they would not attend was because they had no issues they needed to discuss
- Overall preference for a 2 night workshop
- 66% said any age group was fine
- 60% would like mix of educational and social

**Response by age group**



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## Recommendations from survey

- 2 night women's workshop to be held in 2009
- Open to all age groups
- Provide breakout sessions for different age groups
- Provide more social time for younger group and more education for older group
- Highest rated areas for education:
  - Pregnancy & childbirth
  - General haemophilia information
  - Empowering women!



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## 2009 Women's Workshop Weekend



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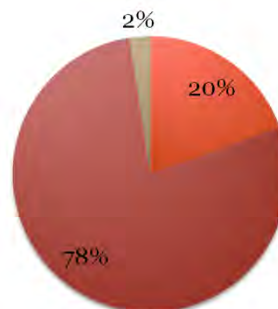
## Participants

### Workshop:

- just for women
- affected by bleeding disorders
- of all ages (16+ years)

41 Attendees (aged 15-77)

6 Staff (Outreach & Nurses)



- vWD, 8
- Carriers, 32  
(6 mild, 7 moderate, 19 severe)
- Moderate Haemophilia, 1

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## Aims and Objectives

- To provide information and education
- To empower participants to understand and work through the issues associated with their condition
- To develop a sense of community within the group

## Programme

Friday	Saturday	Sunday
Morning	Morning	Morning
Set-up	Educational sessions: • vWD • Symptomatic carriers • PGD • Managing menorrhagia	Education sessions: • Family planning • Infusion workshop Facilitated discussion groups Weekend wind-up
Afternoon	Afternoon	Afternoon
Arrivals Welcome & Powhiri	Hot Tips for Raising Healthy Boys	Bowling
Evening	Evening	Farewells Tidy-up Departures
Evening	Evening	Evening
Introductions Interactive Session (Genetics & How blood clots)	Social activities: • Create your own style • Quiz night	

## Meeting the Objectives

### 1. To provide information and education:

- Genetics
  - Reproductive Choices
  - von Willebrand Disorder
  - Being an expressed carrier
  - Steps in the management of Menorrhagia
  - Raising a child with a Bleeding Disorder
- (NB – some Sessions / Workshops concurrent)



## Meeting the Objectives

### **2. To empower participants to understand and work through the issues associated with their condition:**

#### Workshops:

- Facilitated Discussion Groups



## Meeting the Objectives

### **3. To develop a sense of community within the group:**

- Variety of Recreational Activities to assist for mutual support in a relaxed, supportive and safe setting
  - Quiz night
  - 'Give it a Go' afternoon
  - Crafts



## Discussion Questions

- Name and Give a brief description of your group (e.g., age, bleeding disorder status)
- What impact / affect has your bleeding disorder status had on your life so far (the good, the bad, and the downright ugly)?
- In what ways do you anticipate that your bleeding disorder status will impact / affect your life in the future?
- What have been the benefits for you in attending this Women's Weekend Workshop?
- What do see as your educational needs or need for support in the future?
- How often would you need to attend a Weekend such as this?
- What recommendations would you make for future Women's Weekend Workshops (eg age range, topics for discussion etc etc)?
- Decide how your group will report back to the whole group.

## Results

- While education was the main focus of the programme, recreational activities and time for bonding was incorporated.

Excerpts from Evaluation Forms:



*"Always learning through different sessions"*



*"It was a good mix - nice for it to be about me for a change"*



*"Networking with others. Parents like discussion and PGD workshop"*





## Recommendations

### What would we do the same?

- Include all ages
- Include time to break-out into age groups
- Keep mix of education/social activities
- Include wide variety of sessions that suit different learning styles
- Include FUN!

## Recommendations

### What would we do differently?

- Ensure better, more comfortable seating
- Space out education programme
  - More time between sessions, or
  - Alternate more interactive sessions with lectures
- Include off-site activity if possible
- Include a more physical activity

## Conclusion

- Overall, participants valued the opportunity to get together
- Women came away with a greater understanding of issues and options related to their bleeding disorder.
- Including a wider range of ages and a wider variety of education topics proved to be a successful formula.

## Acknowledgements

***Baxter***

**Baxter Healthcare Ltd for providing the funding to  
make this wonderful weekend possible for women  
within the haemophilia community of  
New Zealand**