

**SUMMER CAMP FOR YOUNG PEOPLE  
FROM FAMILIES WITH HUNTINGTON'S DISEASE  
20-25 January 1995  
Report by Dorothy Tortell, Social Worker**

**INTRODUCTION**

As a result of very positive feedback from all those who attended the first camp held in 1994, the Wellington Huntington's Disease Association organized a 6 day camp for young people from families with Huntington's Disease. The Camp started on Friday 20 January in the evening and finished on Wednesday 25 January before lunch. After one withdrawal, the final number of campers was 34.

The Camp was held at Forest Lakes, one hour north of Wellington, where we rented the old Homestead and very large grounds. This venue proved to be an excellent facility for the Camp. Forest Lakes provided some outdoor activities which we took advantage of, such as kayaking, horse-riding, abseiling, as well as the use of the swimming pool. Other activities took place away from the venue such as mountain biking, a tramp and rafting. Excellent daily discussion groups were run by an experienced Counsellor/Facilitator.

**CAMP OBJECTIVES**

The Camp had the following Objectives -

- ! For young people from families with Huntington's Disease to meet others from similar background circumstances
- ! For the young people to share information and experiences about Huntington's Disease
- ! For the young people to support each other and by doing so, develop a mutual support network
- ! For all the participants to have fun.

The Camp was a great success and all the objectives are considered to have been met. Campers managed to meet other young people in the same situation and learn how they coped; they spent time with other people who understand what they are going through and gained support from people in the "same boat"; they renewed friendships from last Camp and made new friendships; and overcame feelings of isolation; and they shared information and through this, gained new confidence.

**CAMP ORGANIZATION**

Venue	Forest Lakes, Otaki
Camp organized by	Dorothy Tortell
Counsellor/Facilitator	Ann-Marie Stapp
Outdoor Activities arranged by	Dorothy Tortell
Kayaking, Horse-riding and abseiling supervised by	Forest Lakes
Mountain Biking organized by	Garth Baker
Tramping organized by	Dorothy Tortell
Down River Rafting Trip supervised by	Tararua Outdoor Recreation Centre
Camp Helpers	Jenny Guilford Wendy Burne Virginia Haynes

Transport provided by

Grant Heywood  
 Philip Tortell  
 Lisa Tortell  
 Judy Lyon  
 Bernie Degerholm  
 John Schiff  
 Jo Banks  
 Ian Hunter  
 Peter Degerholm  
 Doug Currie  
 Jackie Piper  
 John and Diane Cole  
 Stuart and Bev Churches  
 Robynne Spence  
 David and Catherine Reed  
 Dorothy Tortell

## FUNDING AND COSTS

### FINANCIAL SUPPORT RECEIVED -

! Pub Charity	\$1000.00
! Bank of New Zealand (Mayfair Branch)	725.00
! Todd Foundation	1,500.00
! The Sutherland Self Help Trust Board*	657.18
! C H Izard Trust	200.00
! Auckland Huntington's Disease Association	1,200.00
! Huntington's Disease Association Christchurch (Inc)	300.00
! Nelson Multiple Sclerosis Society	800.00
! Wellington families contribution	260.00
<b>TOTAL</b>	<b>\$6,642.18</b>

\* The total amount made available by the Sutherland Self-Help Trust Board for "Programmes for Children of HD Parents" was \$4,000. The balance will be used for other activities in our Young People's Programme such as the holidays get-together.

## CAMP COSTS

! Fees and honoraria for Counsellor and Camp Helpers	\$ 1050.00
! Forest Lakes venue hire	1810.00
! Food and groceries	1548.00
! Cellular telephone rental	142.88
! Tararua Outdoor Recreation Trust	680.00
! Mountain Bikes hire	225.00
! Instructors for mountain biking	405.00
! Bus hire for transport to activities	460.00
! Stationery	31.55
! Sundry	234.85
<b>TOTAL</b>	<b>\$ 6,642.18</b>

All funding support is gratefully acknowledged.

## **PARTICIPANTS**

The total number of campers was 34 (19 females and 15 males)

9 family groups made up a total of 23 young people

Age range 6 - 16 years -

6 years	one camper	7 years	two campers
8 years	one camper	9 years	four campers
10 years	two campers	11 years	two campers
12 years	five campers	13 years	six campers
14 years	three campers	15 years	three campers
16 years	two campers	17 years	three campers

Districts the participants came from were -

four from Auckland	two from Hamilton	two from Wanganui
fifteen from Wellington	six from Nelson	two from Invercargill
one from Ashburton	two from Greymouth	

## **CAMP PROCEDURE**

On arriving at the Camp the young people had free time which allowed them time to settle into their bunk rooms and meet the other campers. After dinner we all gathered together and Ann-Marie facilitated activities which gave us the chance to introduce ourselves to each other and briefly explain why each of us had come to the camp. The Camp rules were discussed with the campers.

During the next four days, the campers took part in a series of outdoor activities. On Saturday all activities took place at Forest Lakes and each camper had the opportunity to experience abseiling, kayaking, and horse-riding.

Sunday saw the older campers go mountain biking. This was a very popular activity as the language showed us after the camp!! At the same time the younger campers went for a three and half hour tramp. This was also popular and all the campers made it with very little coaxing!

Monday saw family and friends join us for a barbaque and later in the afternoon the campers were able to go horse-riding, kayaking or swimming.

On Tuesday the whole group set off by bus for the Otaki River where the older members of the group went Down River Rafting and the younger group had the chance to do more kayaking as well as attempting rafting. We finished off with a barbaque lunch at the river. In the evening we had an end of camp celebration dinner of turkey and pavlova and sparkling fruit juice.

Over the first three days Anne-Marie ran workshops on a number of issues relating to Huntington's Disease.

- ! What Huntington's Disease means to the campers.
- ! Feelings the campers have towards Huntington's.
- ! Strategies to cope with Huntington's Disease in the family.

Several hours were also spent in answering the young peoples questions on Huntington's Disease.

One of the most difficult, yet the most moving exercise was an activity the young people did titled "**Expressions of feelings of Huntington's Disease**". This activity took place outside. The young people broke up into their allocated groups and each group was asked to sculptor a picture describing what Huntington's meant to them and then write down in a few words explaining their sculptor. They could use anything they could find in the garden. The result was a most wonderful display of feelings that can be evoked by Huntington's.

- ! Group A sculptured a person using a punga
- ! Group B sculptured a tomb stone which symbolised death, the basic end of life felt by many people suffering from Huntington's. It also serves as a memorial to those people whose lives Huntington's has claimed and the anguish felt by families and friends.
- ! Group C sculptured the face of a person to show the emotions and acts that people supporting others with Huntington's Disease face. eg : stress, shock and intense pain.
- ! Group D sculptured a traingle made out of sticks with pink flowers in the traingle and yellow flowers outside the traingle. The group spoke of the flowers in the traingle represent hope and the flowers outside the traingle which were placed in a line represent the people without Huntington's and the one lone purple flower shows that there is a feeling of beauty in everyone even people with Huntington's.
- ! Group E described their composition as a "mess". To them it showed that a person with Huntington's feels like everything is falling apart ..... and the family is having messed up feelings.
- ! Group F's composition was entitled "The Feeling Tree" and consisted of a twig stuck vertically in the ground representing the person with HD. Pine cones on the twig represented family, friends and support persons. The twig was decorated with a number of natural and other objects - these included : crumpled can which conveyed the feeling of being crumbled up inside, yellow and orange flowers which represented hope, one pink flower among a number of flowers which meant that a person with HD feels as though they are different from the rest of the crowd, an old leaf representing sadness, torn paper showing frustration and anger, being torn up, an empty bottle representing feelings of emptiness and loneliness.

On the final night the campers made presentations on what the camp meant to them. One group called their item "Parting". They each held flowers and explained that the flowers symbolise how we are all individuals, seperate parts of a big family. We are going our seperate ways but will come back together again next year. They handed out flowers to everyone and each person in turn dropped a flower in a container of water and said what they thought about the camp. They then finished by saying that the water represents us as one big happy family, just like a bunch of flowers.

## EVALUATION OF THE CAMP

Total replies = 34 (not all replies provided answers to all questions)  
How would you describe the various activities???

	EXCELLENT	GOOD	POOR
Introductions on Friday evening	12 (35%)	21 (61%)	0 (0%)
Group activities (with Anne-Marie)	21 (61%)	10 (29%)	2 (6%)
Kayaking	23 (68%)	11 (32%)	0 (0%)

Abseiling	22 (65%)	6 (18%)	4 (12%)
Horse-riding	15 (44%)	17 (50%)	2 (6%)
Tramping (18 trampers)	4 (22%)	9 (50%)	5 (28%)
Mountain biking (17 bikers)	14 (82%)	3 (18%)	0 (0%)
Rafting/Canoeing	28 (82%)	2 (6%)	1 (3%)
Evening activities	18 (53%)	14 (41%)	0 (0%)
Bar-B-Q lunch with families	24 (70%)	10 (29%)	0 (0%)
Sessions on Huntington's	27 (79%)	7 (20%)	0 (0%)

The least popular activities were Tramping and Abseiling.

The most popular activities were River Rafting and Canoeing, closely followed by the Sessions on Huntington's and Mountain Biking.

The amount of organized activity was considered Just Right by 82 % and none thought it too much.

However, 9 respondents (26%) would have liked more free time.

Activities they would have given up for more free time included Abseiling, Tramping, Horse-riding.

Only 2 respondents (6%) said that they did not get a chance to talk about Huntington's to other Campers. Of those that did, 65% found it Very Helpful and 32% found it Quite Helpful.

The majority of Campers (61%) found the accommodation at Forest Lakes, Comfortable, while 39 % thought it was Very Comfortable.

The food was considered to be Good & Enough by 82% of Campers. Five (15%) thought it was Good But Not Enough; and one Camper considered the food Not So Good.

The camp rules were considered to be Fair & Reasonable by 29 Campers (85%), but 5 Campers (15%) found them Too Restricting.

Overall, 100% said that they enjoyed the Camp.

When asked what they enjoyed the most -

ENJOYED BEST	CAMPERS
Kayaking/ River Rafting	17
Everything	5
Mountain Biking	5
Talking & Sharing, meeting new friends	5
Horse-Riding	4

Abseiling	3
Sessions on Huntington's	2
Tramp	1
Bar-B-Q Lunch with families	1

When asked what they had enjoyed the least -

ENJOYED THE LEAST	CAMPERS
Abseiling	8
Horse-Riding	7
Tramping	4
Mountain Biking	3
Too many young kids	2
Camp Rules	1
Too noisy to sleep at night	1
Saying goodbye	1

Only one camper said that the Camp should not be held again next year.

If the Camp was held again next year, 31 campers (91%) said that they would come, 2 campers said they did not know, and 1 camper would not come.

Among the Any Other Comments were the following -

- the camp should be longer
- cabins should be mixed
- campers should be allowed to choose cabins
- one of the adult helpers was a bit rowdy
- the adult helpers were excellent
- young and old campers should be at separate camps
- would like to hear even more on HD
- can we have motorbikes next year?
- a bit homesick
- night times were not quiet, could not sleep
- many thanks
- the camp was great, excellent, awesome, etc
- the cooking was great
- the camp should be held more often
- Forest Lakes Homestead needs more showers

## CONCLUSIONS

!The camp was a resounding success.

! All the objectives were met.

! I feel the Association has a responsibility to continue running such camps in the future.

! Therefore fund raising should begin immediately.

! If the Wellington Association is to organize the next camp, I feel it should be held once again in the Wellington/Wairarapa region for ease of planning.

! I believe that a facilitator/counsellor such as Ann-Marie should be contracted again to work with the young people. Ann-Marie's input into the camp was invaluable; the time she spent on preparation for the Camp and her wonderful interaction with the young people was a major contribution to the camp's success.

! Outdoor activities for such a camp are essential and must be continued and extended.

! I would suggest we should do our own catering at the next camp.

! It is important that the families are involved in the camp either in the beginning or the end. I would suggest the involvement of family members for the whole of the final day, finishing with a joint session for family members and campers.

The young people left the camp more confident, with an increased knowledge of Huntington's Disease, and with a well established support network which I hope will continue for many years to come.

## **ACKNOWLEDGEMENTS**

My sincere thanks to all those who helped make this camp possible - to those who helped us financially, to those that gave us moral support, and to those who gave up their time to help at the camp.

My thanks also to all the campers who got into the spirit of the camp right away and who participated fully and sincerely in all the activities. I really enjoyed meeting you all and sharing the weekend with you. I look forward to being with you at the next camp.

*Dorothy Tortell*  
Social Worker