

**CAMP FOR YOUNG PEOPLE
FROM FAMILIES WITH HUNTINGTON'S DISEASE
9-12 April 1996
Report by Dorothy Tortell, Social Worker**

INTRODUCTION

As a result of very positive feedback from all those who attended the second camp held in 1995, the Wellington Huntington's Disease Association organized a 4 day camp for young people from families with Huntington's Disease. The Camp started on Tuesday 9 April in the early afternoon and finished on Friday 12 April after lunch. After several withdrawals at the last moment, the final number of campers was 21.

The Camp was held at Camp Akatarawa just under one hour from Wellington. This venue proved to be an excellent facility for the Camp with very comfortable accommodation and lovely grounds. All outdoor activities took place away from the venue and these were complemented by daily discussion groups 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; they overcame feelings of isolation; they shared information and through this, gained new confidence.

CAMP ORGANIZATION

Venue	Camp Akatarawa, Upper Hutt
Camp Organized by	Dorothy Tortell
Recreation Coordinator	Ginny Haynes
Counsellor/Facilitator	Ann-Marie Stapp
Abseiling, Bridge Swinging and Caving	Rap-seil Adventures NZ
Entertainment	Julie Daniels (Juggler)
Video Parlour	Time-out Video Parlour, Lower Hutt
Golf	Hutt River Golf Park
Camp Helpers	Brigit Laidler Jane Spiers Belinda Cordwell
Transport provided by	Terry Keating

FUNDING AND COSTS

FINANCIAL SUPPORT RECEIVED

! Lottery Youth	2,000.00
! Auckland Huntington's Disease Association	400.00
! Huntington's Disease Association Christchurch (Inc)	200.00
! Nelson Multiple Sclerosis Society	700
! Wellington families contribution	60.00
! Pub Charity	1,000
TOTAL	\$4,360

All funding support is gratefully acknowledged.

CAMP COSTS

! Fee for Recreation Coordinator	750.00
! Fee for Counsellor	500.00
! Honoraria for camp helpers	390.00
! Camp Akatarawa	1,713.50
! Transport to and from airport and activities	882.00
! Rap-seil Adventure NZ	500.00
! Stationery and sundry	68.75
! Time-out Video Parlour	150.00
! Golf Park	70.00
! Ansett NZ - to bring participant to Wellington from Auckland	305.00
TOTAL	\$5,329.25

The Social Worker's salary for the 4 days at Camp and time spent in planning, organizing and preparing for the Camp, are not included above.

PARTICIPANTS

The total number of campers was 21 (11 females and 10 males)
4 family groups made up a total of 10 young people

Age range 8 - 18 years -

8 years	one camper	10 years	three campers
11 years	two campers	12 years	three campers
13 years	two campers	14 years	three campers
15 years	four campers	16 years	one camper
17 years	one camper	18 years	one camper

Districts the participants came from were -

two from Hamilton	two from Wanganui
nine from Wellington	five from Nelson
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 afternoon tea 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 Campers' and helpers' expectations and duties were discussed. The campers had the opportunity to take part in a juggling workshop before dinner. In the evening the counsellor facilitated discussion on respect, peer relationships and self-esteem, after which the younger participants had free time to take part in activities in the gym while the older group had further discussion time.

Wednesday, the first full day, was spent entirely away from the camp in the Wairarapa where the campers had the opportunity to experience bridge-swinging, abseiling and caving. We were very fortunate in having very experienced and supportive guides for these activities. This was an exciting and challenging day and also very tiring due to the long distances we needed to travel to get to the facilities.

In the evening Dr Joanne Dixon, Medical Geneticist, Wellington Hospital, very kindly agreed to talk to the older campers about Huntington's Disease. This talk was well received and generated more discussion over the next few days. During this talk the younger members prepared supper for the whole group and were free to use the activities in the gym.

Thursday morning was spent away from the camp first at the video parlour which had been closed off to the public for us. Before returning to the camp for lunch, we spent time at the Golf Park. Once back at the camp the campers had free time to use the activities at the site and start preparing for the evening concert. Dorothy ran a discussion group on issues pertaining to Huntington's and Anne-Marie ran a further workshop for the group before dinner.

After dinner all campers took part in the concert at which each presented an item.

Friday, the final day, was a busy one. After the Campers had packed and cleaned up, Anne-Marie facilitated the final session where the campers presented a good-bye item and completed an evaluation questionnaire.

EVALUATION OF THE CAMP

Total replies = 20 (one participant was not there for the final session)

	EXCELLENT	GOOD	POOR	NOTES
Introductions on the first day (Tuesday)	4	16	0	
Activities with Anne-Marie	11	9		
Outdoor activities	18	2		
Wednesday evening activities	3	15		2 no answer
Session with Dr Dixon		15	1	(4 not there)
Sessions on Huntington's	9	11	0	

Thursday morning activities	14	5	1	
Thursday afternoon activities	8	12		
Thursday evening activities	7	12	1	
Friday morning activities	7	13		

The amount of organized activity was considered "Just Right" by 18 with 2 not answering this question. However, 12 respondents would have liked more free time.

Activities that they would have given up in order to gain more free time included

- abseiling, caving, the concert and Ann-Marie's sessions.

There was also a suggestion that the camp ran over more days.

13 respondents said that they did get a chance to talk about Huntington's to other Campers. Of those that did, 7 found it "Very Helpful" and 6 found it "Quite Helpful".

The majority of Campers (12) found the accommodation at Camp Akatarawa, "Comfortable", while 8 thought it was "Very Comfortable".

The food was considered to be "Good & Enough" by 12 of Campers.

3 thought it was "Good But Not Enough"; and 5 Campers considered the food "Not So Good".

The camp rules were considered to be "Fair & Reasonable" by 17 Campers but 3 Campers found them "Too Restricting".

Overall, 100% said that they enjoyed the Camp.

When asked what they enjoyed the most -

ENJOYED MOST	CAMPERS
Wednesday outdoor activities	4
Bridge-swinging	6
Night time	2
Talking & Sharing, meeting new friends	3
Video parlour	4
Abseiling	2
Sessions on Huntington's	2
Thursday morning activities	1
Golf	1
Caving	3

When asked what they had enjoyed the least -

ENJOYED LEAST	CAMPERS
Abseiling	1
Caving	6
Talking	1
Wednesday outdoor activities	1
Travelling	1
Concert	2
Dr Dixon's talk	2
Friday morning	1
Cleaning	1
Bridge swinging	1
Time to go to bed	1
Huntington's talks	1

All the campers said that the Camp should be held again next year and that they would all come again.

Among the "Any Other Comments" were the following -

! There were not enough activities and it was too far out in the country.

! I think this camp was too excessive in activities; think we thought less of HD on this occasion - I wanted more on HD.

! This year the camp didn't have very much outdoor activities - we could have gone horse-riding, 4-wheel motorbike riding, and rafting. But it was still a very good camp.

! The boys should be allowed to mix with the girls at night.

! I found that this camp was great because you had your own time as well as fitting other activities in.

CONCLUSIONS

! The camp was successful

! All the objectives were met.

! 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.

! I feel the camp should continue to be held yearly but after having organized the Camp for the past three years, I feel that the Wellington Association should encourage another region to run the next camp.

- ! The Wellington Association should begin fund-raising immediately so that the young people from this region will have the opportunity to attend the next camp wherever it may be held.
- ! I believe that Ginny Haynes' role as Recreation Coordinator was a vital contribution to the success, safety, and smooth running of the Camp. This was a very demanding position which needed much patience and understanding of the campers' needs. Ginny was sensitive to the campers needs and had a great rapport with the young people. This position must be maintained.
- ! 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.
- ! Having the catering done for us made the running of the camp much easier even though the meals were not as good.
- ! The minimum age for campers should be raised to ten.
- ! A separate, shorter camp should be considered for the older group from 18 to approximately 22 years old.
- ! The honorarium paid to the Counsellor and to the Recreation Coordinator are far below professional fees level. This was only possible because both were willing to donate their time on this basis. It is important that this be acknowledged and that adequate provision is made for full professional fees for future camps, since we cannot always rely on volunteers.

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 few days with you.

Dorothy Tortell
Social Worker