

THE BIRCH GROVE

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THE PAS INTERVIEW - WASHES WINTER

When the Birchgrove Group discovered that the Macfarlane Trust was willing to undertake research into the needs of its registrants, we began waiting with eagerness and anticipation.

We have always advocated that the needs of those involved and living with haemophilia and HIV are many and varied and we have always felt that the provision has been random and at times limited. We were pleased to discover that the Macfarlane Trust had decided to use an independent body to carry out this "needs-led" research, and we were happy to participate in talks with PAS, the research company carrying out the survey. We gained the impression that the research company were aware of the complexity and the sensitivity of approaching Macfarlane Trust registrants. So it is with not a little disappointment, that we have become aware that this research may not be as competent as we had hoped. We have received a number of reports about the initial PAS interviews, and this is the

basis of one of them:

I was offered an interview with PAS and I was keen to take the opportunity to help in the research. I attended my local haemophilia centre at the appointed hour and prepared to undergo my ordeal. The interviewer was very pleasant and tried to put me at my ease, despite the microphone and tape recorder I was determined to be relaxed and honest. The first question was a bit of a corker "How did you feel when you were first told that you had HIV?" there are many ways to answer that question and few of them are polite. I began to feel like the victim of a car accident being asked "How was that for you?"

I gradually began to feel that this was her first interview for this survey and that she had little or no background understanding of HIV, let alone haemophilia and HIV. Oh well, I thought I'll just have to be more informative and more direct. The questions that she had to ask weren't exactly searching or exploratory I suspect that they were designed to get the "subject" talking.

(continued on page 6)

SEXUAL HEALING:

by Beth Weinstein

OUR SEXUAL HISTORY

Sexuality is a huge issue for the haemophilia community. Before HIV was even a concern, we were warned about men passing on the gene for haemophilia to daughters; or, for the women who are carriers, giving birth to a haemophiliac son.

Many of us have been made to feel guilty for choosing to bear children. What effect does that have on our feelings of self worth, our desire to be sexual, and in negotiating intimate relationships?

Having a clotting disorder can also affect one's body image and consciousness as a sexual being. Joint damage, limited movement, and altered physical appearance play a role in how those with severe haemophilia see themselves and function sexually. For all of us in the haemophilia community, what are our feelings about our bodies? Do we have fears of acceptance by actual or potential sex partners?

(continued on page 6)

THE BIRCHGROVE WOODLAND PROJECT

In 1995 The Birchgrove Group will undertake with The Woodland Trust to create a living and lasting monument to all those haemophiliacs who were infected with the HIV virus. We feel that a grove of trees would be a fitting representation of our lives and a reminder of the continuing cycle of nature and its message of hope and renewal.

This major project will be concentrating on planting a grove of trees within a community forest as a permanent commemoration to all haemophiliacs who were infected with the HIV virus. This grove of trees is not intended simply as a memorial to those who have died but is also meant to demonstrate the resilience and strength of those

who are still affected. We are hoping to create a visible demonstration of the scale and significance of the tragedy that has affected the haemophilia community. The Woodland Trust has offered us an opportunity to plant this grove of trees in a new 100 acre community forest site, at Stratton near Swindon. The planting would begin in the autumn of 1995.

This joint project will be launched at our conference weekend in Manchester, on November 26th-27th 1994 which is the start of World AIDS Week. Funding permitting, we are hoping to complete the project during the summer of 1996. We know that this community forest will be a peaceful place for people to visit and remember all

those people who have had their lives affected by HIV.

As you can imagine, a project of this scale will eventually cost a considerable amount of money. We will be asking people to sponsor a tree to dedicate on behalf of someone who is living with or has been affected by haemophilia and HIV. Sponsorship of an individual tree will cost £25 and this will help to pay for the planting and ongoing care of the tree. If you sponsor a tree you will receive a Certificate of Sponsorship, which will give information about this woodland grove and record an individual's name. Further details about this exciting project will become available later in the year.