

THE BIRCH GROVE

THE BIRCHGROVE GROUP, P.O. BOX 313, CANTERBURY, KENT CT1 1GL. TEL: 0345 697231

ISSUE N° 3

FROM VICTIMS TO SURVIVORS!

by Cady Khudabux

In an article published in the Guardian on 29 July 1994, the page one article read—“HIV victims may live 20 years”. We seem to be portrayed as “victims” by the press. At other times, we have been called the “innocent victims”. The fact is somewhere there are persecutors, I wonder who they are? Could they be the persecuting press?

The actual article was constructive and based on a paper in the British Medical Journal *Use of CD4 lymphocyte count to predict long term survival free of AIDS after HIV infection*, Andrew Phillips *et al*, 309, 309-13. But why do they have to go to such damaging lengths to get people's attention to read the article and at our expense? Could they not say “Hope for haemophiliacs, fooled by ignorance”.

In the Guardian article, John Meldrum of the National Aids Trust said the study highlighted the needs of long term resources for people with HIV. So far, the government and doctors thought we would be dead three years after the “settlement”, which was why the sums were so low in comparison to other government *ex gratia* payments.

Nick Partridge of the Terrence Higgins Trust made two interesting comments about

the paper. First, an employer dismissing a person with HIV may lose possibly 20 years of good work. Secondly, the study does not indicate any criteria of those long term survivors other than the age at when they were infected.

WIDER IMPLICATIONS

The conclusions of the paper suggested even with the current available treatments, up to a quarter of patients infected with HIV will survive for 25 years from the time of infection, this is without developing AIDS.

One important aspect left out in the paper was the implications of the extended survival time. What sort of planning needs to be made? I wonder if the care of haemophilia and HIV has been neglected due to the so-called prediction of short life expectancy. Our lives are always based on statistics and probability, in this case, CD4 markers. In 1985, the life expectancy was two years and we should not make any long term plans. Then it was three years, then five years and now ten years. This short-sighted view has been to detrimental to us. We need to see behind the person and beyond even our own expectancy, because in the last analysis, who knows?♦

THE CHALLENGE OF THE FUTURE

It is our pleasure to inform you that the national conference of the Birchgrove Group will be held in Manchester on the weekend of the 26th & 27th of November 1994. The theme of the weekend is the Challenge of the Future, we believe that this will be an opportunity for people to meet and look at the important issues that we all share and are concerned about. During the weekend there will be several opportunities for people to meet and talk. There will be a range of discussion groups and a structured discussion involving everyone and focusing on the repercussions of HIV on the haemophilia community. We hope that people will participate in and help to decide the direction of the weekend, and that people will actively take the opportunity to make this conference their own. *See Back Page*

LIVER DISEASE AND HIV

by Ian Richardson, T. Melester
and David Gold

The liver, a large organ located in the upper right portion of the abdomen, is the body's chemical factory. Disorders of the liver and the associated bile ducts and gall bladder can have serious complications. They involve many organs in the body, all of which depend on the liver's products to support their activity.

Liver problems are frequent causes of illness and death in people with HIV infection, even in those previously considered healthy. Both physicians and patients should be aware of the symptoms, methods of diagnosis, drug toxicities and available treatments for HIV-related liver conditions. Symptoms such as pain on the right side of the stomach, enlarged liver (hepatomegaly), jaundice (yellowing of eyes or skin), fever of unknown origin, fatigue, malaise, itching and abnormal liver function tests (LFTs) deserve early and complete evaluation. *(continued on page 6)*

IN THIS ISSUE...

Page One	From Victims to Survivors! Liver Disease and HIV Conference Details
Page Two	Commentary Medical News Alternative Therapies
Page Three	Long Term Survivors Weekend The Birchgrove Statement
Page Four	Mind and Body Connect
Page Five	Finding a Dentist Paul's Prestigious Portion
Page Six	Well You Live and Learn II Letters to the Editor
Page Seven	In defence of the old order Medical News continued
Page Eight	The Challenge of the Future