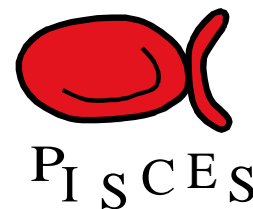


Priapism In Sickle Cell Study

ISRCTN No: 54312363



New email: julie.morris@manchester.ac.uk

No. 3 March 2006

Linda joins the group



LINDA MARTIN BSc (Hons)

Linda Martin RGN BSc (Hons), Clinical Nurse Specialist at Stepping Hill Hospital, Stockport, has been elected to the Trials Steering Group.

Linda is Clinical Lead of the Andrology Service at the Department of Urology. Her specialist area of interest is nursing research, andrology and early prostate cancer.

Linda's role is to facilitate registration of sickle cell centres in the UK and to help develop health education materials along with the society.

PISCES gets cash boost

Orrell Park Baptist Church, Liverpool, has donated £1000 to help fund the PISCES project. Mrs Beryl Smith (right) and Mrs Lille Willis present the cheque to Dr Ade Olujuhunbe (Chief investigator of PISCES).



CYBERSPACE

PISCES is a web based clinical trial. All the forms are on line and should be adapted for local use. A "screen dump" is being created (a visual "step by step" instruction manual) of how to enter patients online. For those Investigators who are not computer prolific, you can get a copy of this manual. Please contact Linda Martin lm.martin@virgin.net or Paula Hamilton email Paula.hamilton@aintree.nhs.uk or tel. 0151 529 3375



HAVE YOU HEARD THE PISCES JINGLE?

Professor Olu Akinyanju and Professor Yetunde Akenova, Principal Investigators at the Sickle cell foundation, Nigeria and University College Hospital have devised an ingenious way to encourage recruitment into the PISCES study and initiate an awareness campaign. They have recorded a radio jingle which can be heard on Radio Nigeria and Radio BCOS This will help "signpost" patients to seek help early. "We have tried this before and the results were beneficial" said Olu Akinyanju.

Next PISCES TSG Meeting
Thursday 30th March 2006
Withington Hospital, Manchester

For further information, contact
Ms Gale Miller on tel. 0161 217 3766
Chairman: Mr Nick George FRCS.

A Personal Account

Eddie Diaso is an individual with Sickle Cell with a storied history of his battles with Priapism. He now, for the first time, shares, with readers of the PISCES Newsletter, his experiences of the condition.

PRIAPISM

To those that are unfamiliar with the problem, let's start with a brief explanation of a Priapism. Priapism is a prolonged and painful erection that can last anything from several hours up to a few days. The erection does not occur due to sexual thoughts and is a common ailment to men suffering with blood disorders, such as Leukaemia or Sickle Cell Disease.

Turning to my experiences of the ailment, I would wake up in the mornings with a non-sexual erection, which is normal in most men. However, as a Sickle Cell sufferer, with sickle blood in the penis, it was painful and difficult for the blood to drain due to the lack of oxygen. The usual escape would be light exercise. I experienced this situation on several occasions during any given month.

My escape from the pain of Priapism failed to work on one particular episode with detrimental circumstances. On this day, after several failed attempts to drain the blood from my penis I decided to sleep on it and have another attempt the next day. Next day came – and went - with no joy. They say that hindsight is a wonderful thing! On the third day I was in a considerable amount of pain and it was at this stage that I decided that I needed medical assistance. By this stage, the damage to the tissue inside my penis was so bad that it rendered me impotent. The better course of action would have been to seek treatment within six hours of occurrence. The treatment offered to drain the blood usually would be a needle in the side of the penis followed by a blood transfusion.

Now at 23 years of age, I thought that my world had come to an end. I was in hospital, after surgery, for approximately three weeks with suicidal thoughts in my head. Questions that were on my mind included 'what was I meant to do with my life without my libido?, at my age?!' What pulled me through is all the love and support from my friends and family. I was struggling mentally for some time due to this drama and spent time in a mental ward of a local hospital. I was also on anti-depressants.

After a period of counselling, I finally decided to climb out of the valley I was in and decided to proceed with surgery to insert a penile prosthesis. The outcome of this procedure was to leave me 'potent', allowing me to have sexual intercourse when desired without complications. It took me a fair while to finally pluck up the courage to use it; I had trouble with this foreign object in my body. When I did, I discovered that it was a wise move. My partner was pleased too!

Eddie Diaso

Eddie Diaso has now dedicated part of this life to further enlighten individuals on issues surrounding Sickle Cell Disease. He has recently become a Trustee to the Sickle Cell Society, a charity dedicated to support affected individuals.. It is here that you can obtain further information on the disease, or give a financial contribution to strengthen this worth while cause.

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