

The 3C Study Campath, Calcineurin inhibitor reduction and Chronic allograft nephropathy



3C Participant Newsletter

Summer 2016

Welcome to the sixth edition of the 3C newsletter. Thank you again for your continued contribution and involvement in the 3C study. You have helped us to answer some important questions about the safety and effectiveness of immunosuppressive medications given at the time of the kidney transplant operation.

The information that we are continuing to collect will help us with the next phase of the 3C Study in answering other vital questions about your long-term well-being and what happens to the functioning of transplants over time. There will be more results from the 3C Study regarding these questions in the near future.

What have we learnt from 3C so far?

The 3C Study demonstrated that Campath (also known as alemtuzumab), halved the risk of early rejection episodes (in the first six months after transplantation), and was not associated with any significantly increased risk of developing serious infections compared with the standard therapy (basiliximab). A summary of the article which appeared in *The Lancet* medical journal, as well as the results, can be found at: http://www.3cstudy.org/

What next for 3C?

All 3C study participants are now in the longer term followup phase of the study. The 3C Study will continue to help us to answer other vital questions about your long-term well-being, and will be helpful to future kidney transplant recipients. The information we are collecting from the questionnaires, together with the information that we receive from national registries and the details about your hospital admissions help us to assess what has happened to you since your transplant. This will be extremely valuable to the whole transplant community including transplant doctors and current and future transplant recipients as it will inform the best way to treat people with kidney transplants.

3C annual follow-up questionnaires

Your response to the 3C participant questionnaire in 2015 was fantastic! We hope that you continue to find completing the questionnaires easier with the new layout. Even though you're no longer attending 3C study visits or seeing the 3C study nurses, the questionnaires that you return provide that vital information to us. So please keep the returning the questionnaires and information to us. There's only one more questionnaire coming your way after this one (in 2017).

If you have any questions about completing the questionnaire or about the sort of information we are requesting, please do not hesitate to contact us by phone, email or letter. We are always happy to hear from you.

Other new trials in transplantation

The Belatacept Evaluation of Nephroprotection and Efficacy as First-line Immunosuppression Trial (BENEFIT) recently reported additional results from its 666 participants. The BENEFIT trial tested immunosuppression treatment with a drug called belatacept and recruitment of participants ended in 2006. The latest publication reported follow-up data 7 years after patients entered into the trial, highlighting the importance of continued, long-term follow-up of transplant patients to assess their longer term wellbeing. Collecting data over longer periods of time enables more reliable assessments of the long-term safety and effectiveness of new treatments.

"3C" has more participants than the BENEFIT trial, of which we should be proud. Your continued participation, in the form of your replies to the annual questionnaires, provides us with a greater opportunity to better understand the long-term consequences of anti-rejection medications. This is why we are so keen to get questionnaires back from you each year, even if you have returned to dialysis and are no longer taking the immunosuppression medications that you were taking during the trial. Many thanks from all of us for your continued support with this!

Feel free to contact us with questions or concerns.

A new lease of life after transplantation for a 3C participant!

Alison's story

Prior to her transplant, Alison required treatment with dialysis. She was working full-time as a health visitor, despite being very fatigued and receiving regular dialysis. She received a kidney transplant from her husband and agreed to participate in the 3C study. Following the transplant, she began to feel better immediately and felt extremely fortunate to have been transplanted and given a new lease of life. After a period of a few months off from work following her transplant, she gradually returned to working full-time.

Off to the seas!

With this new found energy, Alison and her husband decided to take up sailing, which they had not done before, to maintain their fitness and to explore a new hobby. As an introduction, Alison and her husband went on a sailing holiday on a small boat with an instructor to "test the waters". Having had a successful and pleasurable time away, they quickly booked their next sailing excursion with a trip on a 30-foot yacht. Having thoroughly enjoyed these two sailing holidays, Alison and her husband decided to take up dinghy sailing. Living near the sea and having a water sports centre nearby, they decided to give it a go.

Fun, freedom and friendships

For Alison, sailing has given her a sense of freedom and wellbeing, an opportunity to forge new friendships and to stay fit and active and have lots of fun in the process! She's still learning every time she sits in a boat but is now able to rig a dinghy by herself and goes out sailing once or twice a week.



ABOVE Alison is now an enthusiastic dinghy sailor.



Keeping healthy and fit is undoubtedly good for your general health, whether you have a functioning transplant or not. Low-impact aerobics, strength training, and stretching can help prevent stiff joints, build muscle and improve endurance whilst offering benefits to your heart, bones, and mood.

Transplantation and sailing

Having a transplant has meant that Alison has had to be more cautious than most sailors. Alison's transplant team have been extremely supportive and encouraging and she is very grateful to them for the care that she has received. She was warned about the dangers of the waters, particularly with regards to risk of infections and of the importance of using sun protection.

Alison would like to give special thanks to the nephrology and transplant teams at Morriston Hospital, Swansea and at the University Hospital of Wales, Cardiff, for the excellent care and treatment she received and also to her husband Les for donating his kidney.

The study coordinating centre can be contacted by

- phone: 24 hour Freefone 0800 585323 or weekday office hours – Ruth Davis 01865 743528
- post: Ruth Davis, Administrator, 3C Study, CTSU, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford, OX3 7LF
- e-mail: ccc@ndph.ox.ac.uk
- or visit our website at www.3cstudy.org

And remember, you can also contact your local team.



Thank you very much for your ongoing participation in the 3C Study. We hope that trials like this one can improve the long-term outcomes for patients with kidney transplants for many years to come so thank you again for agreeing to take part in the 3C Study.

www.3cstudy.org