

## Participation at conferences and workshops

Here are some of the conferences and workshops we have been invited to and contributed to in recent years:

### 2008

- **Genetics Interest Group/Association of British Pharmaceutical Industry workshop** 'Strategy for Creating a National Alliance on Rare Diseases and the National Action Plan for Rare Diseases in the UK', July 2008, CGD RT staff.
- **Meeting of the European Group for Blood and Marrow Transplantation**, Florence, April 2008. 'The Patient Choosing Transplant for Chronic Granulomatous Disorder', Paediatric CGD Nurse Specialist.
- **British Society for Gene Therapy**, Public Engagement Day, April 2008. 'Journeys in the Genetic Jungle', CGD RT staff.
- **Royal College of Nursing**, Immunology and Allergy Nurses Group Conference, May 2008. 'Chronic Granulomatous Disorder', Adult CGD Nurse Specialist.
- **Trent Regional Immunology and Allergy Consortium**, June 2008, 'National Chronic Granulomatous Disorder Nursing Service', Adult CGD Nurse Specialist.

### 2007

- **British Medical Association**, July 2007. 'Genetic testing of children: How should we decide?' CGD RT staff.
- **Association of Medical Research Charities**, October 2007. 'Organisational approaches to lay review by CGD RT', CGD RT staff.
- **RCN Immunology and Allergy Nurses Forum**, May 2007. 'The role of the CGD Nurse Specialist', Paediatric CGD Nurse Specialist.
- **International Society of Nurses in Genetics Conference**, May 2007.
  - 'A retrospective look at the use of the service provided by the clinical nurse specialist for Chronic Granulomatous Disorder', Paediatric CGD Nurse Specialist.
  - 'Challenging the Impact of Genetic Disorders: The Chronic Granulomatous Disorder Research Trust'. CGD RT staff.

### 2006

- **British Society for Gene Therapy Public Awareness Day**, March 2006. 'Journeys in the Genetic Jungle: progress in gene and cell therapy', CGD RT staff.

- **Association of Medical Research Charities**, June 2006. Invited charity consultation session, CGD RT staff.
- **Health Coalition Initiative** 'Patient Involvement for Better Research and Better Health', June 2006, CGD RT staff.
- **Royal Society of Medicine**, June 2006. 'Genomics meets Epidemiology - The Future of Medical Research', CGD RT staff.
- **European Society for Immunodeficiencies, International Patient Organisation for Primary Immunodeficiencies; International Nursing Group for Immunodeficiencies**, October 2006. CGD RT staff and Paediatric CGD Nurse Specialist.

## 2005

- **European Patient Conference**, December 2005. 'Patients and Stem Cells', CGD RT staff.
- **EPPOSI (European Platform for Patients' Organisations, Science and Industry) Conference**, October 2005. 'Sixth Workshop on Partnering for Rare Diseases – No longer alone in the World', CGD RT staff.
- **A BPI Meeting**, December 2005. 'Participating in EU Health Policy Development', CGD RT staff.