



*Historical article*

## Origins of the Leeds Castle Polyposis Group

Kay Neale and Steffen Bülow on Behalf of the Leeds Castle Polyposis Group  
*Administrative Office, St Marks Hospital, Northwick Park, Watford Road, Harrow, UK*

On 16 February 1983, a very pretty young woman with dark hair and sparkling brown eyes walked into Ian Todd's consulting room. Mr Todd was the senior surgeon at St Mark's Hospital (see Figure 1) and the patient had been referred to him because, in addition to having FAP, she had in her belly a large desmoid tumour. She had continued to work despite the difficulties of dealing with the public assuming she was pregnant and asking whether she wanted a girl or a boy. Social life was worse. 'Are men likely to be more put off by the fact that I'm pregnant or that I've got this great big tumour?' she asked. 'Can't you just cut it out?' But even 20 years ago, although there was very little experience with intra-abdominal desmoids available, surgery was strongly advised against.

### Leeds Castle, 1985

In 1985, colorectal experts from 45 different countries met in London to celebrate St Mark's Hospital's sesquicentennial. There could be no better opportunity to gather together those known to have an interest in polyposis in order to pool knowledge about desmoid disease. To this end, Ian Todd enlisted the help of Walter Bodmer, the Director of the Imperial Cancer Research

Fund. A meeting was organized at Leeds Castle, an historic and picturesque castle in Kent. Space at the Castle was very limited, with the facilities, the conference room, dining room and bedrooms allowing for only 30 people and no spouses. The discussions that took place throughout Sunday and Monday morning proved that knowledge about desmoid disease was indeed limited, and that no one knew any more than anyone else. There was a general consensus that there should be a pooling of knowledge about polyposis and its rarer manifestations. Sheila Ritchie and Kay Neale were given the job of conducting a survey of the polyposis registries around the world in order to establish what sort of information was available. The meeting closed with Jerry DeCosse offering to host another meeting in Washington two years later.

### Washington, 1987

It had been established at Leeds Castle that the meeting in Washington should also be a meeting of experts. Dr DeCosse personally funded the meeting, and, once again, attendees presented information about their work. The emphasis of the meeting was on discussion and, again, it was agreed that the meetings were valuable and that another meeting should be organized in England two years later.

### Worcestershire, 1989, and beyond

By the time of the meeting in Worcestershire in 1989, word about the Leeds Castle Group was getting around. The small country hotel was only big enough for 52 delegates and some people left early to accommodate others for the second half of the meeting. Sheila Ritchie's son in law designed a logo and ties and scarves were included in the welcome pack. The interest in the Group made us realise that we could no longer organise meetings for experts only. It was agreed that anyone interested in polyposis should be able to attend but that this would require more formal organisation. Thus, David Jagelman, Director of the Cleveland Clinic Polyposis Registry, was elected the first Chairman of



*Figure 1.* The original St Mark's Hospital in London, England, professional home of J. P. Lockhart-Mummery, Cuthbert Dukes, HJR Bussey, Ian Todd, Ian Talbot, Kay Neale, and Robin Phillips. Site of the original FAP Registry.

the 'Leeds Castle Polyposis Group' (LCPG) and Steffen Bülow (Denmark) was elected as Deputy Chairman. James Thomson (St Mark's Hospital) was given the task of writing the Constitution. It was agreed that the pattern already laid down should continue with a scientific meeting being held every two years, alternating in and out of Europe. In this way, the next meeting of the Leeds Castle Group was hosted by David Jagelman and took place in Florida in 1991, followed two years later by the one hosted by Steffen Bülow in Copenhagen. In 1995, Terri Berk and Hartley Stern hosted the meeting in Toronto and Hans Vasen welcomed us to Noordwijk, The Netherlands, in 1997 for the first joint meeting with the International Collaborative Group on Hereditary NonPolyposis Colorectal Cancer (ICG-HNPCC). In 1999, the second joint meeting of LCPG and ICG-HNPCC was hosted by LCPG Chairman Finlay Macrae in Lorne, Australia. This was the first occasion where the LCPG meeting was linked to a local meeting, resulting in the largest number of delegates to that time. The new millennium found us in Venice, Italy, where LCPG Chairman Lucio Bertario gave us dinner in a Doge's Palace and where we finally agreed that the Leeds Castle Group should formally merge with the ICG-HNPCC to form a new Society (see Figure 2). It is planned that the Leeds Castle Polyposis Group, under the Chairmanship of James Church, who is the Director of the David Jagelman Polyposis Registry at the

Cleveland Clinic, will merge with the International Collaborative Group on Hereditary NonPolyposis Colorectal Cancer to become the International Society for Gastrointestinal Hereditary Tumours (InSiGHT) at the meeting in Cleveland in 2003.

### Summary

The Leeds Castle Polyposis Group was conceived at a time when little was known about familial adenomatous polyposis (FAP). Herrera and his colleagues had not yet reported their patient with polyposis and a deletion in the long arm of chromosome 5, the serendipitous action of sulindac on colorectal adenomas was in print but its relevance was not commonly appreciated, and the care of families with FAP was based on relatively small series and anecdotal experience. Since 1985, knowledge of the genetics of FAP has exploded, deepening our understanding of the origins not only of FAP but also of sporadic colorectal cancer. Care of patients and families is multi-dimensional and the importance of registries in organizing care, education and research has been emphasized repeatedly. LCPG has played a pivotal role in progress in FAP. Its unique character and the spirit and vision of its founders will live on in the new organization to be founded in September 2003.



*Figure 2.* Council members at the meeting of the combined councils of LCPG and ICG-HNPCC, London, 6–7 March 2003. *From left to right:* Kay Neale (Administrative Secretary, LCPG), James Church (Chairman), Kalpna Pindoria (Secretarial Assistant, LCPG), Gunther Winde, Takeo Iwama, Finlay Macrae, J.-P. Mecklin, Terri Berk, John Burn (Chairman-Elect), Steffen Bülow, Robin Phillips (Administrative Director, LCPG). Not in picture, Gabriela Möslein and Hans Vasen (holding the camera). Absent: Lucio Bertario, Riccardo Fodde, Jeremy Jass and Allan Spigelman. Photo courtesy of Hans Vasen.