



The Association of Coloproctology
of Great Britain and Ireland

ANNUAL REPORT PATIENT LIAISON GROUP (PLG)
Association of Coloproctology of GB and Ireland (ACPGBI)
YEAR 1 - 2016

OVERVIEW

Early Beginnings

The newly convened PLG Group met face to face for the first time in September 2015. Previously Jo Church had been the sole patient representative on Council.

New PLG members were identified via the Delphi Patient Initiative (which was convened to provide a patient perspective on prioritising research projects), and the PLG is composed of Jo Church (Chair) Bob Arnott (Trustee and Secretary BDRF and Deputy Chair), Jenny Pipe and Azmina Verjee (Trustee BDRF). The British Digestive Research Foundation is the charity arm of the ACPGBI, which funds research.

Bob Arnott is an academic lecturing at Oxford University on the History of Medicine and Healthcare policy, and researches into the History of Disease. Azmina Verjee is a cancer clinical researcher by profession and Trustee of Crohn's and Colitis UK. Jenny Pipe was a banker and now an IA trained visitor who supports patients practically in hospital and is on the Executive Committee of IA. The three new members all have stomas and long experience as colorectal patients. Bob Arnott acts as point of contact between the PLG and the BDRF.

The Group is entirely voluntary and acts in the best interests of Colorectal patients at all times as independent individuals, able to voice honest and critical opinions. They present an eclectic mix with complementary skills and have collaborated well over the past year.

PLG TERMS OF REFERENCE AND OBJECTIVES

Terms of Reference were set up last year, and the PLG agreed that a Report on Activity should be submitted each year, which should adhere to and reflect their Terms of Reference.

The main aims of the PLG were to pursue constructive dialogue with the ACPGBI Executive, Council and Membership; to act as a Resource for them on patient

related matters; to raise matters of patient concern; to provide comment and written reports from the patient perspective and to collaborate to provide clear patient information to a lay audience.

NEW INITIATIVES

The increased interest in and acceptance of the importance of the patient experience during treatment to enhance outcomes and future quality of life has enabled the PLG to promote, with increasing confidence, the importance of patient experience and inclusion in the treatment decision and care process in documents and guidelines.

The main points here include the need for individualised care plans for long term patients, which are regularly reviewed as patient's symptom tolerance and attitudes to treatment options may change over time; the establishment of a systematic methodology for patient related outcome measures (PROMS) which are disease specific, and the early intervention of the surgical team for patients for whom surgery is a likely future option, well before it becomes critical and where time enables reflection and full knowledge of the procedure, and its risks and uncertainties with regard to future quality of life.

2ND FACE-TO-FACE MEETING

The Group met again for the second time in August 2016, conducting all other business by email with individuals participating in various committees and activities and then reporting back to the Group, or preparing draft documents circulated for comment and amendment to the Group.

RESEARCH COLLABORATION

Much of the PLG's research collaboration is too prolific to list here, and will appear in ACPGBI Records as a separate list, but PLG participation is included in such research as Guy Worley's Project with regard to patient preference, decision making and the quality of life of patients with ulcerative colitis, who are facing surgical management, and what influences their decisions about surgery. A PLG member is co-applicant on the application to the NIHR (National Institute for Health Research) for the IV Lidocaine Trial. PLG representation is present on the research funding application for Crohn's - to develop a decision making tool for patients facing surgery for perianal Crohn's,

EXAMPLES OF PLG WORK IN THE PAST YEAR SINCE ITS INCEPTION

Council participation and participation at the Executive Meeting on the Forward Plan

Lay Commentary on the Resources Document, directing patients towards the minimum resource needed to deliver a safe and effective service.

Patient Commentary on the Anastomatic Leak Project.

Response to the Consultation on changes to the National Bowel Cancer Screening Programme.

The establishment of text and explanation of PLG work on the Patient site on the ACPGBI website, and work towards a comprehensive updating of the patient information.

Patient representation on the National Bowel Cancer Audit (Project Board and Clinical Reference Group).

Membership of the Clinical Reference Group for Specialised Colorectal Services and in the recent Intestinal Failure Procurement process.

Participation in the External Affairs Committee

Participation in MCC Committee (Multidisciplinary Clinical Committee), and IBD Sub-Group and the IBD Clinical Advisory Group (Inflammatory Bowel Disease).

Attendance at other meetings by invitation, and contributions eg leaflets for the Pelvic Floor Society and RCS (Royal College of Surgeons) Faecal Incontinence Commissioning Guidance Notes update.

The Montgomery Ruling and the Consent Document in conjunction with the President.

First Perianal Crohns's Disease Meeting in London January 2016 providing the patient experience perspective.

Delphi Patient initiative prioritising research, and work on grant applications with a number of groups, consulting on the relevant applications.

ENiGMA Collaboration Day.

SUCCESSION PLANNING

It is envisaged that Bob Arnott will take over as Chair in 2018 when Jo Church retires.

The PLG remains open to all suggestions as to how it may contribute to and facilitate the work of the ACPGBI to focus on its core activity of the care of the colorectal patient.

Jo Church - August 2016
Chair ACPGBI PLG