



THE OCULAR IMMUNOLOGY
AND UVEITIS FOUNDATION

Dedicated to Eye Disease Cure and Education

Support groups and their role in caring for patients with ocular inflammatory disease

C. Stephen Foster, MD, FACS¹

Liz Irvin, PhD, LICSW²

John Hurley, MSW, LICSW¹

Frances B. Foster, MS, NP, CS¹

This article describes our experience with a self-help group for patients with uveitis that was founded in 1996 by Dr. C. Stephen Foster, Frances Foster MS, NP, CS and John Hurley LICSW. Our experience with this process, and the success of the group, confirms other reports about the important role of self-help groups for patients coping with serious illness. And, we have observed in the process that the Group complements our professional efforts to care for patients with these potentially blinding illnesses. The purpose of this article, then, is to report on our positive experiences with the Uveitis/OID Support Group, and to encourage other specialty physicians to support the formation of such groups in their own practices and geographic regions.

The Uveitis/OID Support Group has become an important part of the continuum of care for our patients with uveitis and other *ocular inflammatory diseases* (OID). It is a resource for physicians and patients alike. Individuals with uveitis and OID come together four or five times a year to share experiences and to offer mutual support. Members report gains from the interpersonal support, from the information exchanged, and report having used the process to explore ways of coping with their illness. In addition to hosting regular meetings, the Group now produces a monthly Newsletter, participates with faculty and staff in the development of educational materials for the use of uveitis patients and their family members, and maintain a wide array of online support resources that are easily accessed by anyone in the world with a computer.

Rational for Starting a Support Group

Uveitis is the third leading cause of preventable blindness in the United States. Nonetheless, it is a relatively rare disease. Without organized opportunities to come together, patients with uveitis and their family members have few opportunities to meet others that suffer from the illness or to learn from others' efforts to cope with its potentially life-altering complications.

Self-help groups are a well-established part of the spectrum of care for patients with serious, non-ocular illnesses. In fact, over 800 such groups are listed in online resources. As an example, the National Cancer Society provides local support groups and information exchanges that are of great value to those coping with cancer and to their family members. And, because cancer is a relatively common illness, there are opportunities in everyday life for patients to encounter others who have experienced cancer themselves or in their family. Knowing others who have "been there" provides important opportunities for exchanges of information, resources, and emotional support.

Such is not the case for adults and children with uveitis. Our patients have often commented on the fact that they do not know even one other person with uveitis, and, for that matter, have never heard of the

disease. The title of the most recent educational topic sponsored by the Support Group gets this point across nicely: "I Have Inflammation WHERE?" As the potentially blinding implications of chronic uveitis and ocular inflammatory disease become apparent to patients with severe forms of the illness, and to their family members, anxiety can mount, along with a sense of isolation, anger, and fear. Ophthalmologists are all too familiar with the despair and worry of their patients in this regard, and few have resources for referral of these situations.

We strongly advocate that physicians facilitate the development of a self-help support group for their uveitis patients and for the parents of children with ocular inflammatory disease. A parent of one of my pediatric uveitis patients put it this way in a note to the support group . . . "often, as we (parent and child) are waiting so see Dr. Foster, we see the same people all the time because we are all on that '6 week schedule. So, we have become friends and share stories. It is very helpful. I find that stories on the personal level are equally as important as knowing the medical impact that uveitis will have ö"

Getting Started

The Uveitis (USG)/OID support group formed primarily because of the efforts of a patient (also a nurse) who had been treated for uveitis since childhood. She engaged me (CSF), and a member of the Social Work staff of the Mass Eye and Ear Infirmary (JH), in a discussion about starting a support group and was very persuasive in her views. It was apparent that, for this effort to be successful, the I would need to lend its support for all of the reasons explicated above. I agreed to be the Faculty Sponsor/medical advisor for the group. In this role, I provided encouragement, support, referrals, and modest financial support for operational/startup costs. Mostly, I cheered and admired their efforts and believed in the potential of such a group. John Hurley, a member of the Social Service staff, provided instrumental support and guidance. We received training about conducting a support group from members of a local chapter of the American Cancer Society and later were able to train patient representatives as co-leaders.

Although a support group could conceivably exist without institutional or physician support (indeed, there is a proliferation of same online), our motivation was to provide opportunities for information and supportive exchanges between our patients primarily. Over time the group has opened itself to others out of a sense of generous support to all patients with uveitis, and the group now has members from all over New England.

Benefits

A self-help group is made up of people who feel they have a common problem, experience or situation and have joined together to do something about it. Our experience is similar to others who report that such groups are a powerful and constructive means for patients to help themselves and help each other. We do not know of the experiences of other in-person Uveitis/OID support groups that may have formed. But, based on our four years of experience now with the Uveitis/OID support group, we believe that such activities directly contribute to our patients' ability to cope with these illnesses, and improve their capacity to participate in their own care. And, we concur with Silverman's observation (1995) that being involved in a reciprocal helping exchange with others promotes compassion, cooperation and a sense of community (Self-Help Sourcebook, 1995).

Role of the Physician-Sponsor

In my view, the role of a physician-sponsor is, primarily, to enable the Group to do the things that the group members view as their main *raison d'être*: in the case of our group, mutual support and information exchange. As a practical matter, we provide a place for the group to meet, financial support for materials and refreshments, a page on our WEB site to post and report group activities and to distribute valuable information about uveitis and related disorders. The Massachusetts Eye Research and Surgery Institution (MERSI) supplies a steady source of speaker resources for education on the matter of uveitis and ocular

inflammatory diseases, medical management, etc. The course of such groups can be up and down as attendance waxes and wanes, and the physician-sponsor can play an important role by encouraging group members to persist during lean times.

Summary

The USG produces a monthly Newsletter for members that is widely distributed. Members are actively involved with faculty in developing educational materials for distribution to others living with ocular inflammatory disease and have applied for educational grants to support this work. A meeting for parents of children with uveitis is held every two years. Resourceful leadership has emerged from within the group. Members take responsibility for organizing quarterly meetings, selecting topics, monitoring an online exchange resource, developing grant applications, and receive and manage inquiries about group activities.

It has personally been gratifying to watch this Group grow and show evidence of increasing effect, both locally and nationally. We believe, based on our experience, that such collaborations are of mutual benefit, complementing our medical care of patients with uveitis while providing an important source of information, emotional support, and fellowship for those who live with the illness. We strongly encourage our colleagues around the world to support the development of such groups within their own communities and practices.

Charles Dudley Warner (1873) may have said it best; "It is one of the most beautiful compensations of this life that no man can seriously help another without helping himself." ¹²

Founding members of the Uveitis/OID Support Group in Boston. Current member.