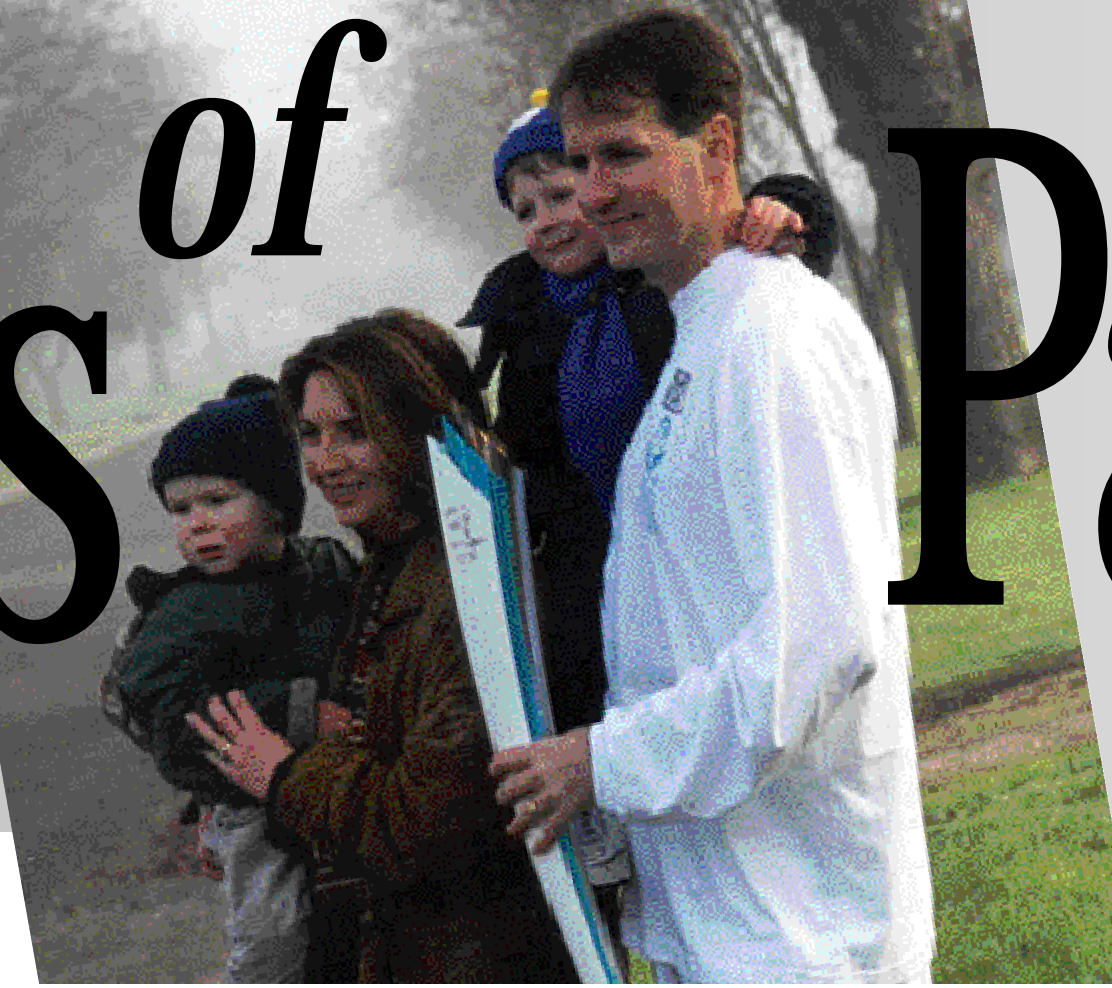


Support Group for Families of Patients with Intracranial Aneurysms

INDIANAPOLIS NEUROSURGICAL GROUP & NEUROSCIENCE CRITICAL-CARE,
CLARIAN HEALTH (METHODIST CAMPUS) • INDIANAPOLIS, IN

INDIANAPOLIS
neurosurgical
CRITICAL CARE



Former patient, engineer from Australia. Had rebleed and severe vasospasm. Young wife with baby far from home during husband's prolonged serious illness. Aneurysm Support Group was important resource for her. Patient recovered totally and was selected to be a torchbearer for the 2000 Olympics

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Abstract

Our center annually treats over 100 patients with aneurysmal subarachnoid hemorrhage. SAH results in a sudden change in the lives of not only the patients but also their families. Family members are abruptly put into the role of decision-maker and care-taker for the patient. This is a role for which they are ill-prepared particularly due to the sudden, critical nature of the illness and lack of medical knowledge. This can result in a frustrating and non-productive relationship between the patient, family and health care team.

Our center has addressed this problem with a support group for families of hospitalized aneurysm patients. The group has met weekly for 5 years and is led by 2 experienced neurosurgical nurses with the support of the neurosurgeons. Each session is individualized but the focus is on information regarding aneurysms, treatment, complications and outcome. Emphasis is also placed on helping families cope with inherent life-style changes and uncertainty.

Our support group for families is a unique approach which families, neurosurgeons and hospital staff have praised for helping families to understand, make decisions and cope with frequently prolonged and difficult hospital courses of patients with SAH.

The purpose of this presentation is to encourage other centers to develop support groups for families of acutely ill aneurysm patients. We will include information regarding development of the group, content of weekly meetings and what we have learned.

Getting Started & Keeping Going

- Started 1994 in response to patient's concern that family did not understand and did not know what to expect
- Purpose of group to provide:
 - Information regarding aneurysms
 - Information regarding resources
 - Emotional support to families
- Content developed by team including nurses, neurosurgeons and former patients
- Commitment to meet weekly prior to evening visiting time to accommodate all families
- Families encouraged to attend by nurse facilitator, neurosurgeon, chaplain, social worker, nurses. Information regarding meetings posted in patient's room and waiting rooms
- Financial support for teaching materials from hospital, neurosurgeons, awards, former patients and Methodist Hospital Task Core



... from the Clarian
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Content Of Meetings

- Facilitated by 2 nurses experienced in management of aneurysm patients; status of patients reviewed with neurosurgeons prior to meetings
- Content varies based on needs of attendees
- Information regarding aneurysms
 - Pathology, etiology, risk factors
 - Diagnosis
 - Treatment options
 - Complications (spasm, hydrocephalus etc.)
 - Outcomes
- Information regarding resources (many patients far from home)
- Emotional support
 - Families faced with sudden critical illness, possible death/disability, life-style changes, uncertainty
- Participation PRN by other disciplines (chaplain, neurosurgeon, social worker etc.)
- ANSWER QUESTIONS
- Use slides, booklets (approved by neurosurgeons), hands-on materials (clips, coils)



Sandy Bailey receiving for the Aneurysm Support Group the 1998 American Association of Critical-Care Nurses' Inno Vision Award. This award recognizes programs that innovatively and collaboratively meet the needs of families of the acute and critically-ill

How The Group Helps

- **THE FAMILIES**
 - Provides non-stressful, quiet time to ask questions and voice concerns
 - Lessens apprehension associated with "not knowing"
 - Helps families know what to expect and helps them with planning
 - Provides encouragement for family members to take care of themselves
- **THE NEUROSURGEONS**
 - Provides ongoing source of accurate information for families
 - Reinforces information given to families by neurosurgeon
 - Improves communication with families
 - Provides means to communicate information to multiple family members
- **THE STAFF**
 - Reduces family anxiety during visiting time
 - Improves family understanding and appropriate involvement

What We Have Learned

- Families have many questions (they frequently come to group with lists)
- Most frequent questions concern outcomes, risk factors and monitoring devices (facilitators should be knowledgeable regarding these areas)
- Decision-makers may not understand our terminology (Ex: "clipping" may suggest cutting off the aneurysm; "spasm" may suggest observable muscle spasms)
- Families view situations differently than professionals (One family member stated, "Your idea of normal sure is different than my idea of normal")
- Individual family needs must be assessed; some just want to talk or ask questions; others need a detailed lecture; sometimes families don't know what they need
- Facilitators must be prepared for anything... examples from our group experience:
 - 2 sisters got into a heated argument blaming each other for their mother's SAH
 - 1 husband's focus was "Sex after aneurysm rupture" (probably a common concern not easily expressed)

Future Plans

We have learned that readjustment to life after hospital discharge may be difficult for patients and families, even those who have "done well". Several former patients have attended our support group and feel it is helpful to them to understand "what happened to them". We have several former patients who are willing to talk with recent patients about readjustment. We see a major need to develop an ongoing support group addressing the needs of recently discharged patients and their families.