

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 30 August 2004

Executive Committee members present:

- Amy Brown Gaghagen, President
- Victoria Goldstein, Treasurer / PR, and Research Committee Chairperson
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

Debi Pederson, Vice President was not present

IVPF Committee chairpersons present:

- None

Kathy Blades, Support Committee chairperson was not in attendance

Marlou Van Dijck, Education Committee

Trina Perrone, Fundraising Committee co-chairperson was not in attendance

Sue Miller, Fundraising Committee co-chairperson was not in attendance

Meeting began at 16:09 GMT (10:09 AM CST)

Executive Committee Minutes from 16 August 2004 were unanimously approved for archival and distribution.

It was agreed to hold no IVPF Executive Committee meetings between Sophie's Walk in August and 13 September of each year.

Agenda:

- Officer Reports
- Treasury Reports
- Chapter Reports
- Membership Committee Report
- Public Relations Committee Report
- Research Committee Report
- Fundraising Committee Report
- Education Committee Report
- Support Committee Report
- Nominating Committee Report
- Budget
- Old Business
- New Business

Officer Reports:

- President
 - No report given.
- Vice President
 - No report given.
- Secretary
 - No report given.
- Treasurer
 - Full totals for Sophie's Walk are not yet in.
 - USA
Donations and interest: \$7,021.30
Expenses: \$102.59
Total cash on hand: \$34,740.85
Thank-you notes sent to donors: 95
 - UK
Donations and interest: None reported
Expenses: None reported
Total cash on hand: £828.11
Thank-you notes sent to donors: None reported

Membership:

- No report given.

Public Relations:

- Committee meeting will be set for September.
- Newsletter needs to be started.
- Denise Pugash MD, FRCP(C) in Vancouver, Canada, one of the local organizers of the ISUOG 2005 event occurring in Vancouver, has invited IVPF to exhibit at the event. She also plans to present a paper about their local experience with vasa previa at this meeting. Victoria thinks it is a good idea to attend this conference and will pursue it.
- The (RSNA) Radiological Society of North America's Scientific Assembly and Annual Meeting is Nov 23 - Dec 3 in Chicago this year.
<http://rsna2004.rsna.org/rsna2004/V2004/index.cvn> It is huge. Amy can attend. Victoria will look into costs and feasibility.

Research:

- Committee meeting will be set for September.
- This committee needs a new chairperson.
- There has been a request for funding for vasa previa research from a doctor for the purpose of studying the detection rate of vasa previa in a local hospital and how to improve it. It was suggested that IVPF immediately supply the doctor with information on risk factors, testing, and management, along with the current study, and find out exactly how much money is needed for the project. Draft of a reply to the doctor has been submit for approval.

- IVPF has been contacted by the Florida Institute for Fetal Diagnosis and Therapy in regards to an experimental in-utero surgery to correct type 2 vasa previa (multi-lobed placenta). They've informed us that they are starting an observational study assessing the potential risks and benefits of such a procedure. They claim their technique is being performed worldwide, and that they've done over 400 such procedures (not necessarily all vasa previa cases) with the following benefits to women with this condition: a) the avoidance of sudden spontaneous rupture of the vessels leading to fetal/neonatal death, b) the avoidance of prolonged hospitalization, c) the avoidance of the need for obligatory cesarean section, d) and potential delivery at term. The IVPF Medical Advisory Board has been notified regarding this communication. Awaiting response.

Fundraising:

- Sophie's Walk took place 22 August 2004. Full report will be given in September.
- We will communicate via the Walk Manual and emails next year as the meetings were very poorly attended. There will be a walk manual for next year. It was too hard to put together in time for this year as the materials were not available until walk preparations were in full swing.
- Sophie's Walk for Vasa Previa 2005 will take place 20-21 August 2005.
- Training for new committee co-chairs: Co-chairs have been contacted. Awaiting availability of co-chairs.

Education Committee Report:

- Cindy was given a contact for the head of a local ultrasound department at in St. Louis regarding vasa previa content of her training program. It is possible this could have effects in other areas than St. Louis as the contact also trains people who are also working in ultrasound in other geographical areas. It was agreed that Cindy should contact the department head requesting to meet to discuss this possibility.

Support Committee Report:

- Support outline for website was resent to Jackie Frith as she had computer problems and lost it.

Nominating Committee Report:

- No report submitted.

Budget:

- No report submitted.

Tax Exempt Status:

- No report submitted.

Old Business:

- Karen Peters was appointed IVPF Director by the IVPF Board of Directors on 16 Aug 2004. There was a round of excitement concerning this appointment.
- Welcome letters have been mailed to the IVPF Medical Advisory Board, awaiting response.
- IVPF in-service presentations: It has been suggested by a contact of Cindy's that there are a number of free online testing CME credit programs available. It is possible that we may be able to use inservice and/or testing programs on these sites and offer CME credit, possibly with no cost to IVPF. Victoria also has a contact at Philips for online CME courses. Waiting to train in-service program volunteers on IVPF policy. Still awaiting the finalization of the Medical Advisory Board, which has agreed to help put together an official IVPF presentation suitable for in-service programs. Will go ahead and contact active MAB members regarding in-service program development.
- IVPF purchase of a professional convention display set: A contact of Tracy's contacted Cindy with an offer to help with this task as well as possibly some others in Fundraising and PR. Haven't heard back from Tracy's contact.

New Business:

- Mary Guenthart was approved as IVPF participating member.

The next regular IVPF Executive Committee meeting will take place on Monday, 20 September at 16:00 GMT (10:00 AM CST, 11:00 AM EST) in the Board room of the Vasa Previa Chat Café.

Meeting Adjourned at 17:22 GMT (11:22 AM CST)