

# **International Vasa Previa Foundation, Inc.**

## **Executive Committee Meeting Minutes for 16 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

### 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 18:42 GMT (12:42 PM CST)

Executive Committee Minutes from 26 July 2004 were unanimously approved for archival and distribution.

A change in meeting time was suggested to better accommodate Executive Committee members during the school year. It was agreed to hold upcoming meetings at 16:00 GMT (10:00 AM CST). The next scheduled IVPF Executive Committee meeting will occur at this time on 20 August 2004.

### **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
  - A Board meeting must be scheduled to appoint a replacement for the vacant Director position. Board meeting will be set up for today, directly following the Executive Committee meeting.
- Vice President
  - No report given.
- Secretary
  - No report given.
- Treasurer
  - No report given.

**Membership:**

- There are 70 participating IVPF members (+3).
- There are 273 subscribers in the IVPF newsletter email group (+2).
- There are 166 subscribers in the Vasa\_Previa email group (+1).
- Links to the risk factors, testing and management document, IVPF brochure, FAQs, slide show and medical resources on vasa previa have been added to the links section of the IVPF and Vasa\_Previa email groups.
- This committee continues to provide routine maintenance and screen / welcome new subscribers to the email groups.
- This committee writes to people who contact the IVPF through its [info@vasaprevia.com](mailto:info@vasaprevia.com) email address and contact forms.
- This committee maintains records of contacts and IVPF members.
- A participating membership request form will soon be created and installed on the IVPF website, thus automating the process. Personal notes and membership certificates will continue to be emailed and postal mailed to all requests after they are approved by this committee.

**Public Relations:**

- 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 its a good idea to attend this conference and will pursue it.

**Research:**

- 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. Cindy will draft a reply to the doctor and 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. It was agreed to notify the IVPF Medical Advisory Board regarding this.

**Fundraising:**

- Co-ordination of Sophie's Walk continues and is in full swing.
- Training for new committee co-chairs: Co-chairs have been contacted. Awaiting availability of co-chairs.
- Jenna Steckler volunteered to work with the IVPF Fundraising Committee contacting other organizations for grants.

**Education Committee Report:**

- No report submitted.

**Support Committee Report:**

- No report submitted.

**Nominating Committee Report:**

- No report submitted.

**Budget:**

- No report submitted.

**Tax Exempt Status:**

- No report submitted.

**Old Business:**

- Cindy Paris was appointed IVPF Director by the IVPF Board of Directors on 26 July 2004. Karen Peters has accepted the IVPF Board of Directors request to join them on the Board in the last empty Board position. These appointments will fill the two IVPF Board of Director positions left empty this year due to Marlou's and Terri's resignations. A Board meeting is necessary to appoint Karen Peters to the Board.
- Official letters from the IVPF thanking the Medical Advisory Board for accepting their positions have been sent, awaiting responses. Amy will resend postal communications via email.
- IVPF in-service presentations: Jenna Steckler volunteered to put together the

IVPF in-service program. She works for Glaxo SmithKline and has experience constantly setting up programs (hospital grand rounds, dinner programs, society meetings, etc.). Julie Boyd also volunteered to help with this program some time back. Cindy will forward Jenna information on IVPF requirements for the program and steps taken so far. She will also train Jenna on IVPF policy and on IVPF's stand and key statements on vasa previa for this purpose. IVPF is 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.

- IVPF purchase of a professional convention display set: A professional contact of an IVPF member contacted Cindy with an offer to help with this task as well as possibly some others in Fundraising and PR. The contact will get back to us in a couple of weeks. Victoria mentioned a contact that her husband has used for trade show displays. His display consists of 3 banners with stand and lights for \$390. Victoria will send photos and prices. Tabled 12 July 2004 pending further information.

**New Business:**

- None.

**The next regular IVPF Executive Committee meeting will take place on Monday, 30 August 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 19:05 GMT (1:05 PM CST)