



“A **Bleed** makes you swell”



“A **Clot** makes you shrink”

**Educational Needs of General Public + Patients
and**

Role of Patient Advocacy Organizations

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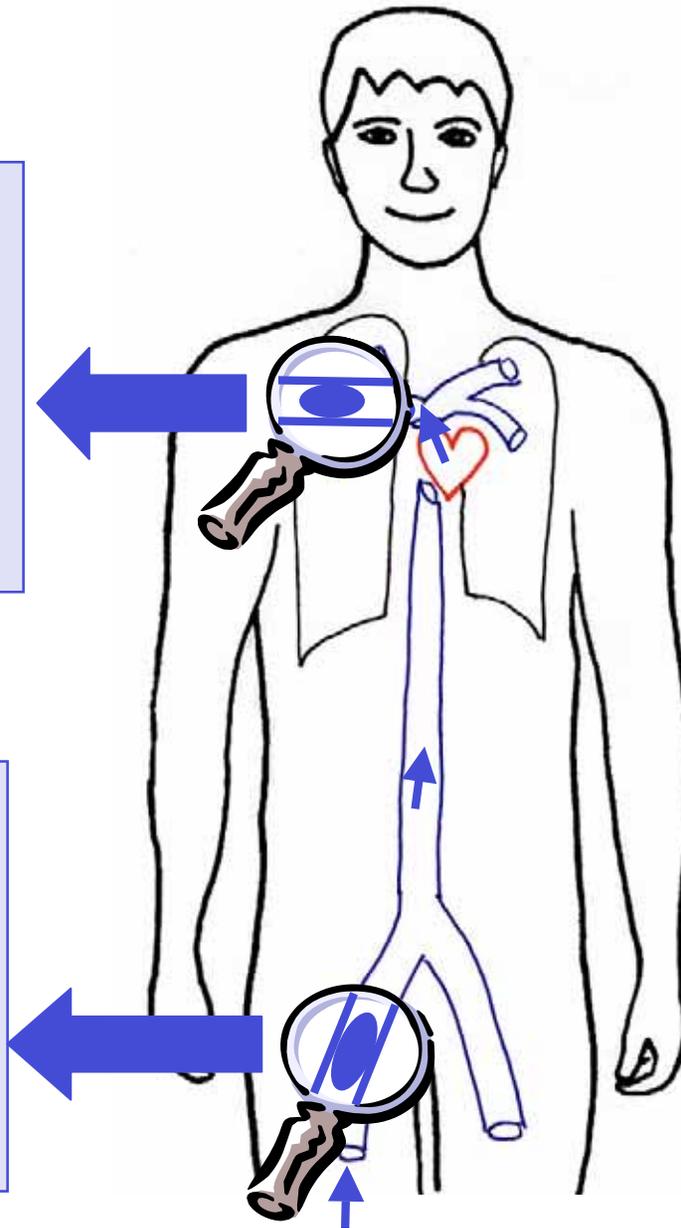
Venous Clots

Pulmonary embolism (PE)

- short of breath
- chest pain
- cough
- bloody sputum

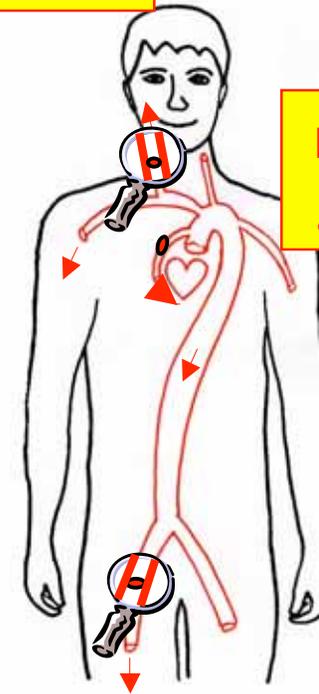
Deep vein thrombosis (DVT)

- swollen
- painful
- warm
- blue-purple



Arterial Clots

Stroke



Gangrene

Risk Factors for Clots

Arterial

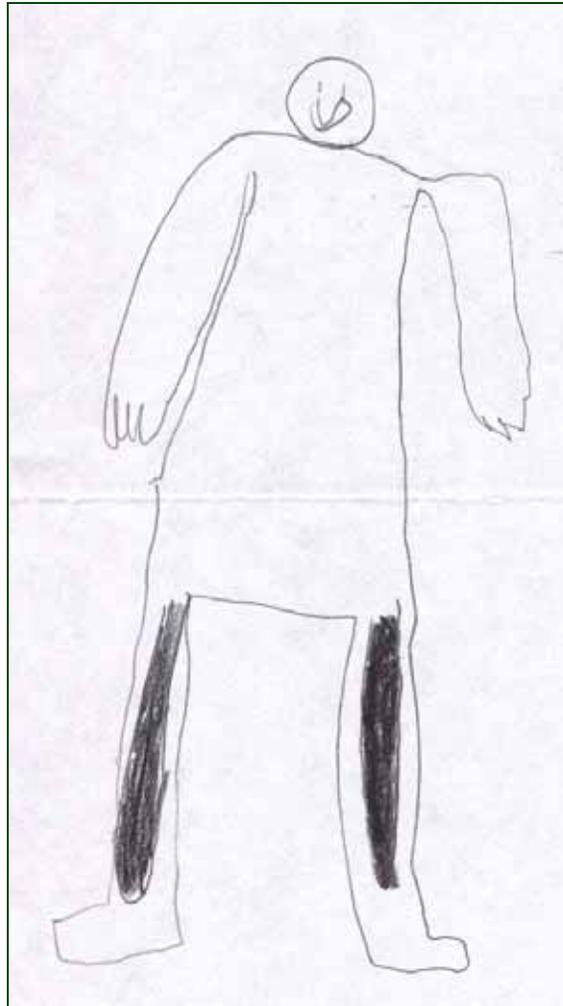
1. smoking
2. overweight
3. high cholesterol
4. high blood pressure
5. diabetes



Venous

1. immobility (overweight)
2. surgery, trauma
3. hormones
4. cancer
5. inherited or acquired clotting abnormalities

How to prevent / treat clots



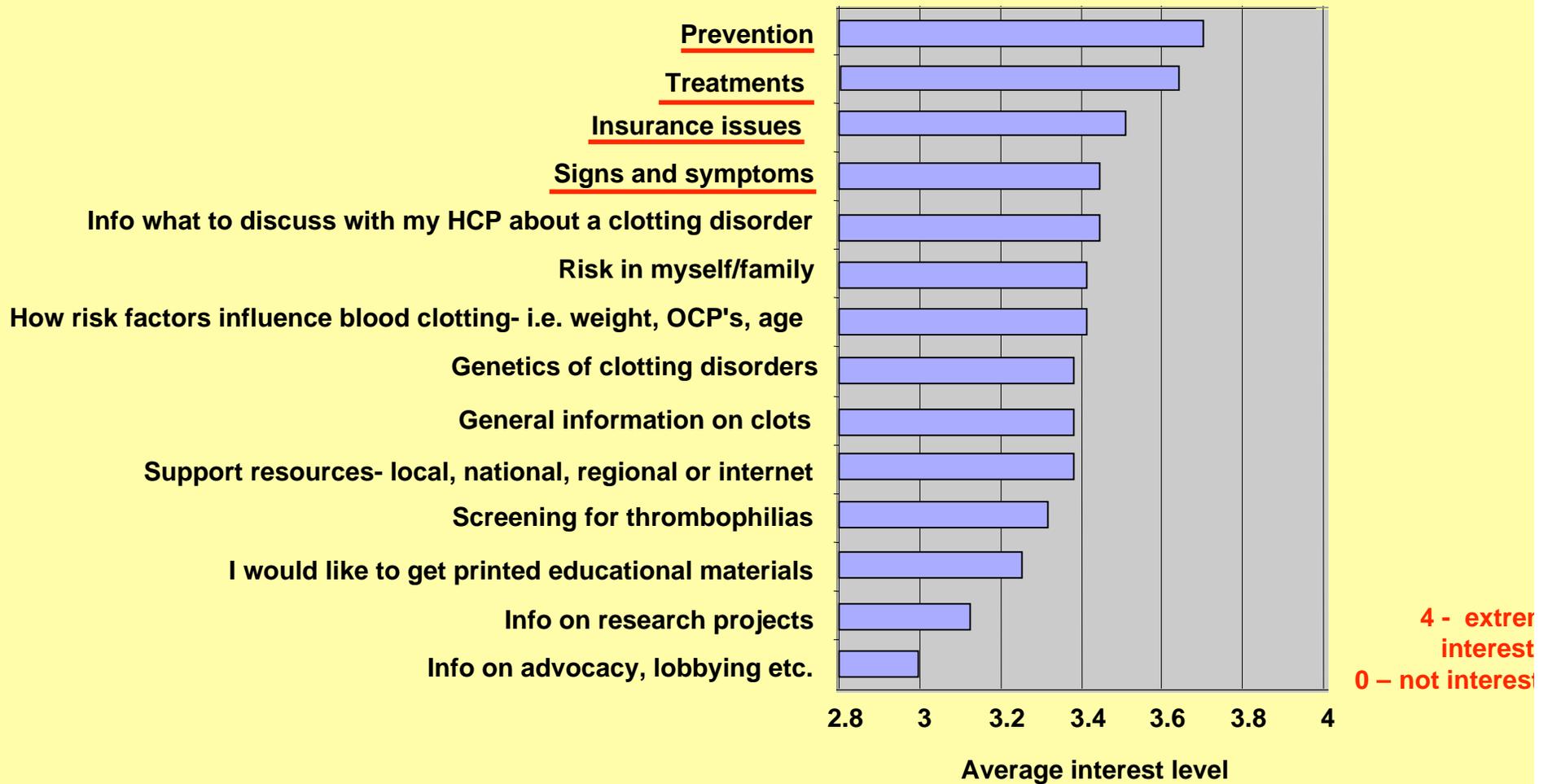
Andrew, age 8

The Public: Lack of Awareness

- APHA 2002
- Telephone survey
- 1,003 U.S. adults

- 74% of the public have little or no awareness of DVT;
- 54% do not know any symptoms of DVT;
- 57% cannot name any common risk factors for DVT

The Patients: Education Needs

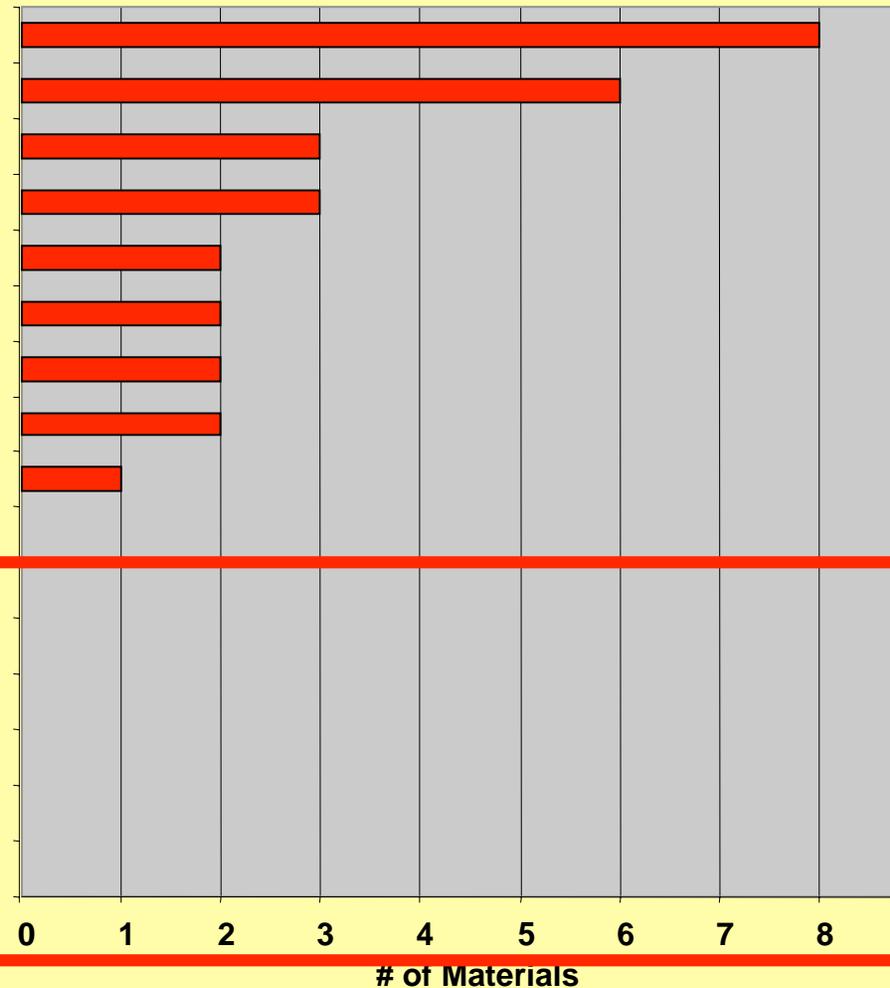


Availability of Education Materials

Review of printed and web-based education materials

Number of Patient-Appropriate Educational Materials on Thrombosis and Thrombophilia To

General info on thrombosis
Treatment
Factor V Leiden
Antithrombin III deficiency
Understanding genetics of thrombophilia/inheritance
Protein C/S deficiency
General info on thrombophilia
Antiphospholipid antibodies
Thrombophilia and Pregnancy
Psychosocial implications
Prothrombin G20210A
Prevention
Contraceptives and thrombophilia
Insurance and thrombosis/thrombophilia
HRT and Thrombophilia
Genetic Testing for Thrombophilia



Gap!

Availability of Education Materials

www.nattinfo.org

501c3 non-profit

www.fvleiden.org

Non-profit, patient-run

www.clotcare.org

ClotCare. Multiple sponsors

www.dvt.net

Sanofi-Aventis sponsored

www.preventdvt.org

Sanofi-Aventis sponsored

Thrombosis Prophylaxis

Is there a need for behavioral modifications for the prevention of DVT?

- Exercise may be
- Nutrition may be
- Hydration may be
- Obesity may be
- Smoking may be

Formal research on whether modification of these factors decreases the risk of DVT is lac

Role of Patient Advocacy Groups

(Portions redacted)

A. Education (Public – Patients – Health Care Providers)

- Helping assess the true education needs through formal research;
- Creating and distributing education messages and materials for public

B. Prophylaxis and treatment

- Scientific studies: Encouraging the development for at-risk population
- Therapy standards: Encouraging the development (example: patient undergoing gastric bypass surgery);
- Making existing therapy standards available to all health care providers
- National DVT prophylaxis guidelines: Participation + endorsement (example: NQF-JCAHO);

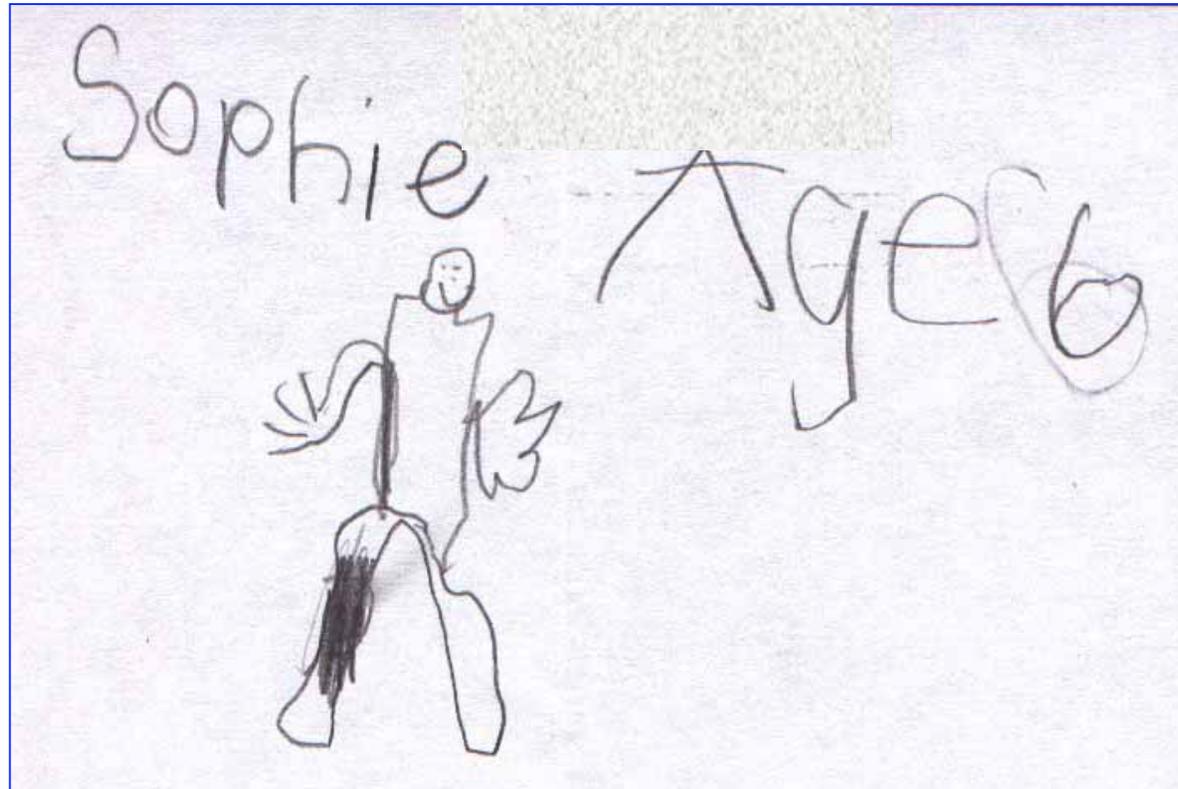
NATT's activities as viewed by me

- Good and competent leadership – Mark Jablonski, Chicago;
- Effective Education subcommittee (Chair Liz Varga, Columbus, OH);
- Collaborative approach (CDC, CDC-funded Thrombophilia Pilot Site group, ASH, AC Forum, HTRS, NHF, NHLBI, DVT Coalition, Venous Forum, pharmaceutical companies, etc.);
- Non-profit, 501c3, neutral
- Short of money – needs full-time staff
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Key needs in next 3 years:

- Successful fundraising
- More volunteers to get involved to do the work

Role of Patient Advocacy Groups



Knowledge

Awareness

Prevention

Treatment

Support