

# The Austrian FH Patient Organization

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# From personal suffering to the collective mission



## 2004: First FH patient advocacy group in the German-speaking countries

2011: Kick-off for two powerful patient organizations in Austria and Germany





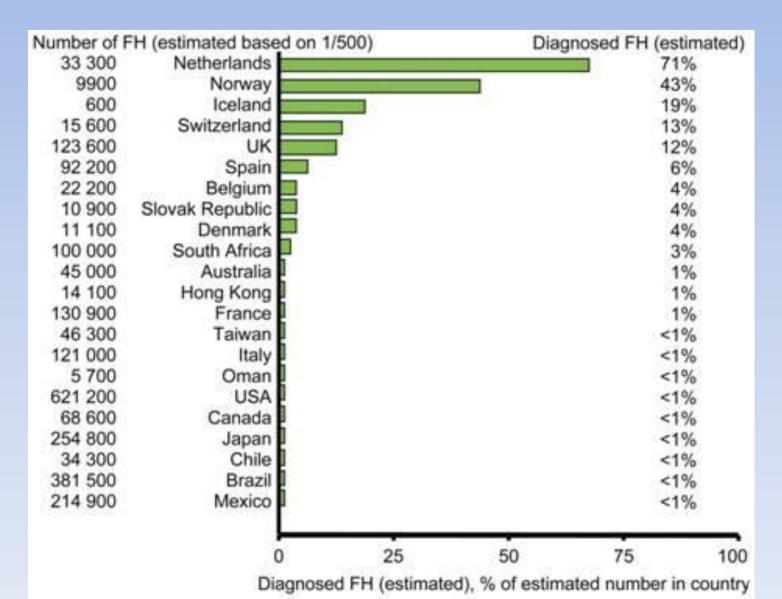


#### Familial Hypercholesterolemia

Underestimated
Underdiagnosed
Undertreated

**DESPITE A NOBEL PRIZE IN 1985** 







### Why Patient Advocacy?

- Strong signal: Prevention of CVD is possible despite chronic condition
- Role models for other patients
- Patients are the faces of FH







# Scientists & Medical Doctors & Patients = Powerful Team









# Scientists & Medical Doctors & Patients = Powerful Team

- Scientists: Experts in basic research & drug development
- Medical doctors: Experts in direct communication with and treatment of patients
- Empowered patients: Experts of their own condition/disease



### **Empowered patients**

- Do not compete with the science & medical community – EQUAL PARTNERS
- Join forces with science & medical community and start fruitful dialog
- Give scientific data and findings a face
- Important voice for science & medicine



### **Empowered patients**

- Educate other patients
- Know about their risks
- Have a better compliance
- Raise awareness through emotions
- Put pressure on public health authorities



#### How we raise awareness of FH

- www.fhchol.at & FB page
- Brochures and Videos
- Workshops & Events
- Public Relations & Media
- Congresses & Symposia





# Public Relations & Media Press Conferences





### **FH Awareness Day 2015**

### Supported by Viennese City Counsellor for Health





### **Cholesterol Checks in Shopping Malls**





#### **FH Awareness Week 2016**

#### Supported by Tyrolean health politicians







#### **Social & Networking Patient Events**

- Regular informal FH patients' meetings
- Annual patients' conference with expert lectures

- FH cycling excursion







#### **Political Pressure & Lobbying**





- Request primary prevention through early screening & treatment
- Request reimbursement of innovative medication



# Endorsement of Austrian-wide FH Registry & Cascade Screening by the Austrian Atherosclerosis Society AAS





### International cooperation

FH Europe - European FH Patient Network









Thank you for your attention!