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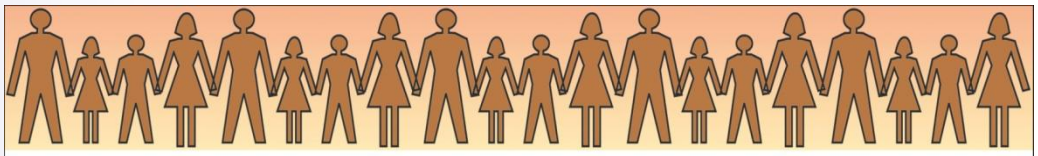

Verein für von der von Hippel-Lindau (VHL) Erkrankung betroffene Familien e.V.

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Patient and private foundations:

a partnership for registry and biobank management: the German von Hippel-Lindau patient organization initiative

Gerhard Alsmeier, VHL Germany

Brussels, 23.05.2012

Overview

- Introduction VHL / VHL patient organisation
- PO driven Biobank
- The German VHL-Biobank
- Perspecitves

Von Hippel-Lindau-Disease (VHL)

What is VHL?

Background:

- Rare **inherited tumor syndrome**, autosomal dominant genetic condition
- 1904: German ophthalmologist, **Eugen von Hippel** first described angiomas in the eye
- 1927: Swedish pathologist, **Arvid Lindau,** described angiomas of the cerebellum an spine
- **Affected organs**: Eyes, Brain, Spinal Cord, Kidneys, Adrenal Gland, Pancreas, Ear, …
- incidence: 1 / 35.000

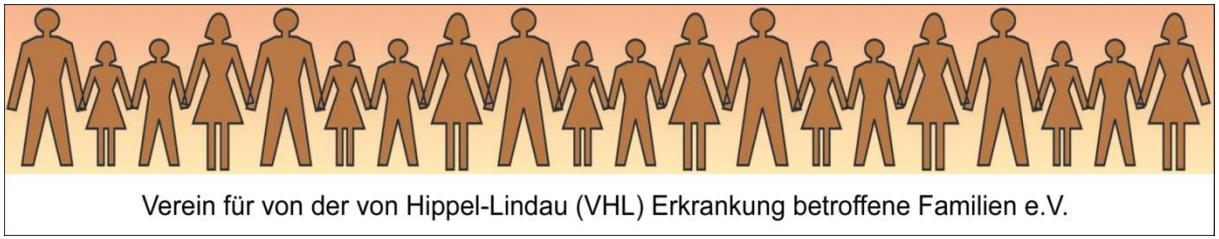
Genetics:

- caused by **mutation in the VHL-gene** (on Chromosom 3p25.3)
- **Tumor-Suppressor-Gen**
- 80% inherited
- 20% *de novo* mutations (in early fetal development)

Treatment:

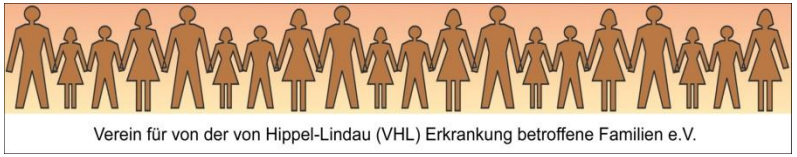
- When symptoms occur → **surgery**

VHL patient organisation



- founded in 1999
- 280 members
- Budget of 25.000´€ / year
- Annual national and regional meetings
- 4 Newsletter / year
- European Meeting every 2 years
- www.hippel-lindau.de www.vhl-europa.org
- Forum www.rareconnect.org/de/community/von-hippel-lindau

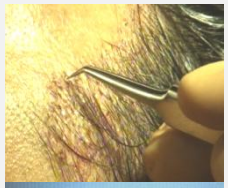
About myself



- 50 years old
- VHL affected
- First surgery at the age of 12
- Visual handicap
- Chair of VHL Germany since 1999
- 2008 – 2011 board member of ACHSE
- Representative of ACHSE in Nationplan for Workgroup Research

What is a Biobank?

Part 1



biomaterials

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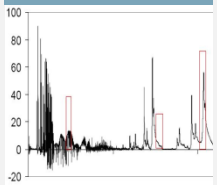
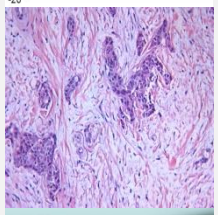
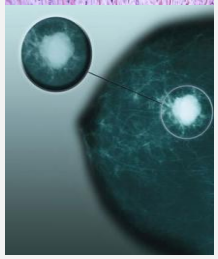
Part 2

iSOFT Health
An IBA Health Group Company

KIS

clinical data

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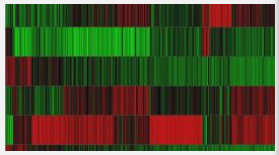
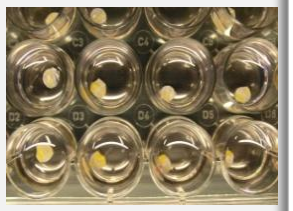
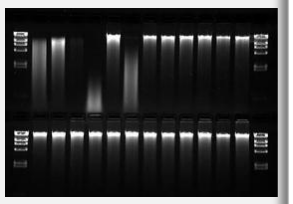
Research



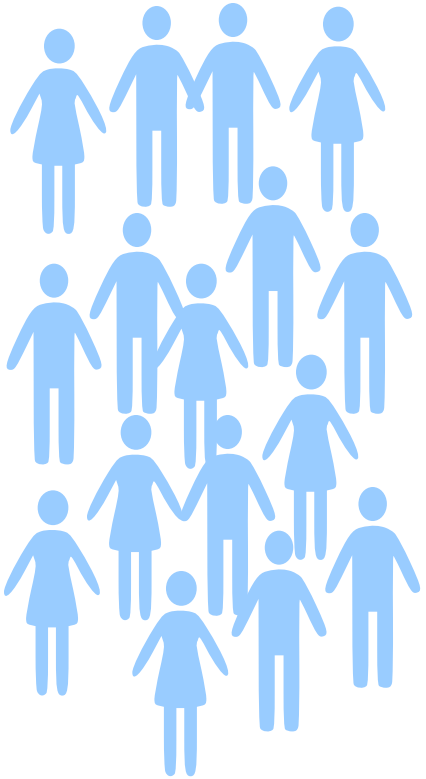
research projects

Why should a PO run a biobank

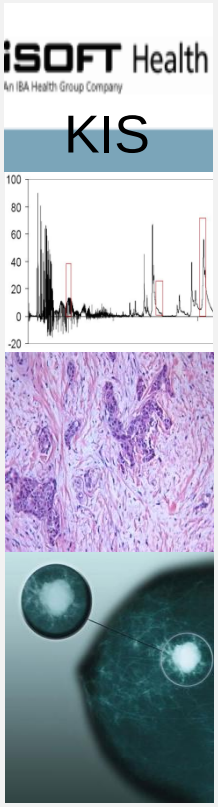
- Biobank is needed for all kind of research
- Only Patients have biomaterial
- it is the most valuable “capital” of Patients
- Patients are informed who has biomaterial
- Others?

Why should a PO run a Biobank?

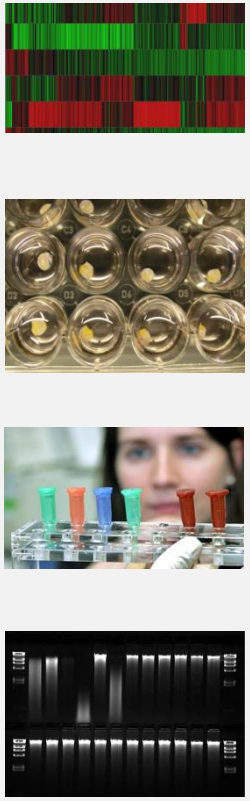
Ideal world …Dream?...



biomaterials



clinical data

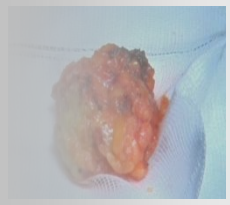


research projects

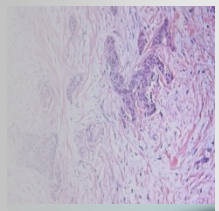
ONE (inter)national biobank **ALL** patients **ALL** researchers cooperate

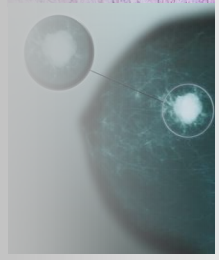
Why should a PO run a Biobank?

Reality Biobanks on local,regional level

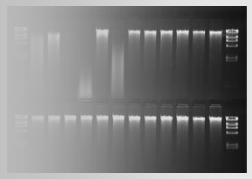


only a few samples





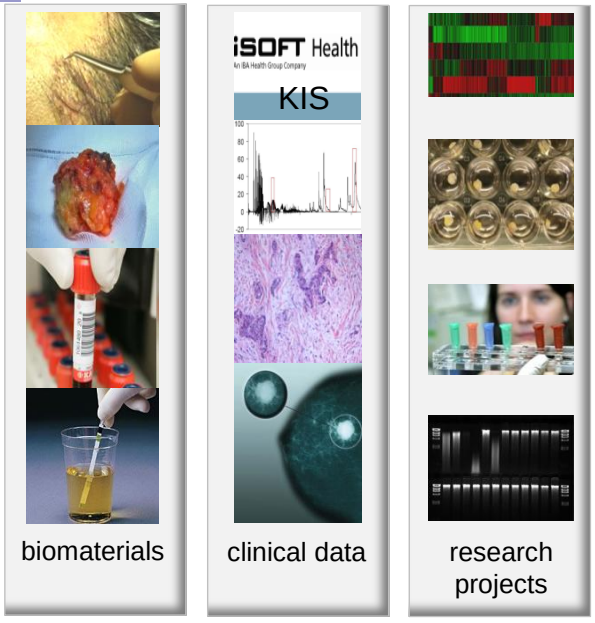
incomplete clinical data



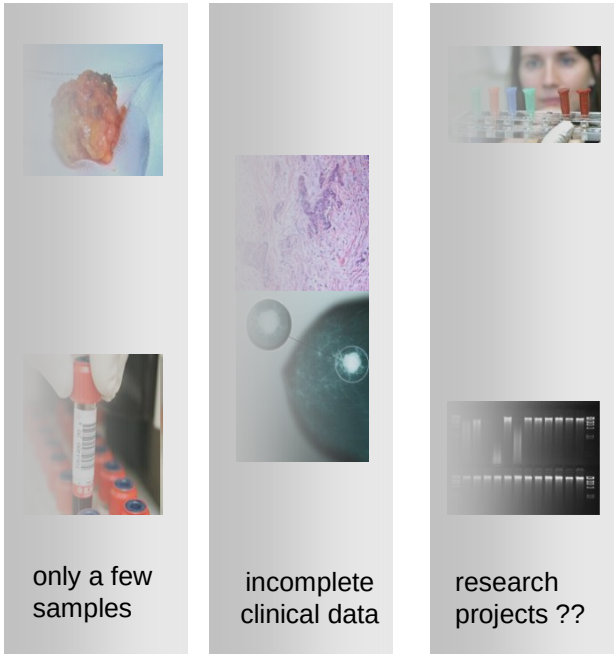
research projects ??

? biobank **?** **a few** biomaterials **no** research cooperation

When should a PO run a Biobank?



Ideal world → no need for a PO driven biobank



Reality → a PO driven biobank is really useful

BUT → you need professional partners

Requirements for partners

- Accept PO as a partner
- Sustainability
- Financial resources
- Willingness to share data, biomaterials and results with others
- Others?

Possible partners

- Hospitals ☑ ☒
- Research organizations ☑ ☒
  (e.g. Max Planck Society, Germany)
- Industry ☒
- Foundation ☑
- Others ☑ ☒
  (e.g. national cancer society, Ministry of Science & Research)

Get started! But there are hurdles for a PO

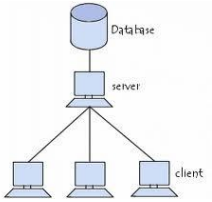
- Ethical vote
- Programming and Maintaining the registry
- Handling, Storage and Administration of biomaterials
- Financing

Get Informed Consent

Surgery/
Blood withdrawal

Samples
pseudonymized

Medical Data
pseudonymized
Clinical Database



Storage / Handling

The German VHL-Biobank – 3 partners

Verein für von der von Hippel-Lindau (VHL) Erkrankung betroffene Familien e.V.

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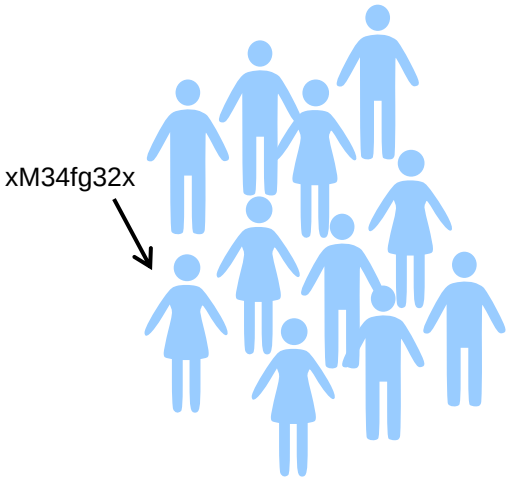
Recruitment Pseudonymization



Management VHL PO:
G. Alsmeier
...

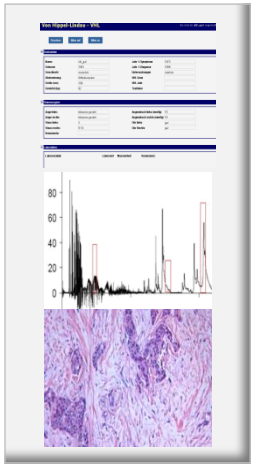
Biomaterial

Prof. M. Schwab
Prof. H. Brauch
Dr. M. Sonnenberg

In cooperation with:
Prof. M.D. Alscher

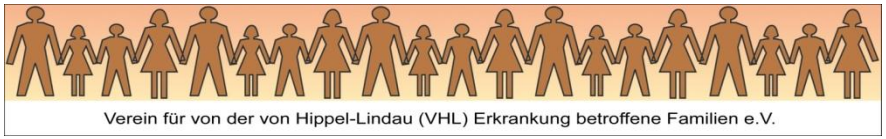
RBK
Robert-Bosch-Krankenhaus

Clinical Database



Dr. P. Fritz
P. Albu

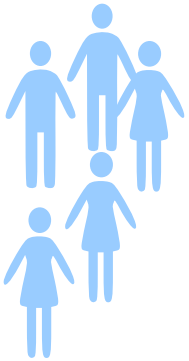
The German VHL-Biobank - Workflow



Recruitment

Informed Consent
send to physician

Pseudonymization



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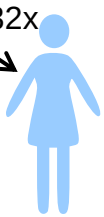

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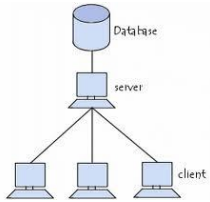


Participants send biomaterials

Storage,

Handling,

Administration of biomaterials

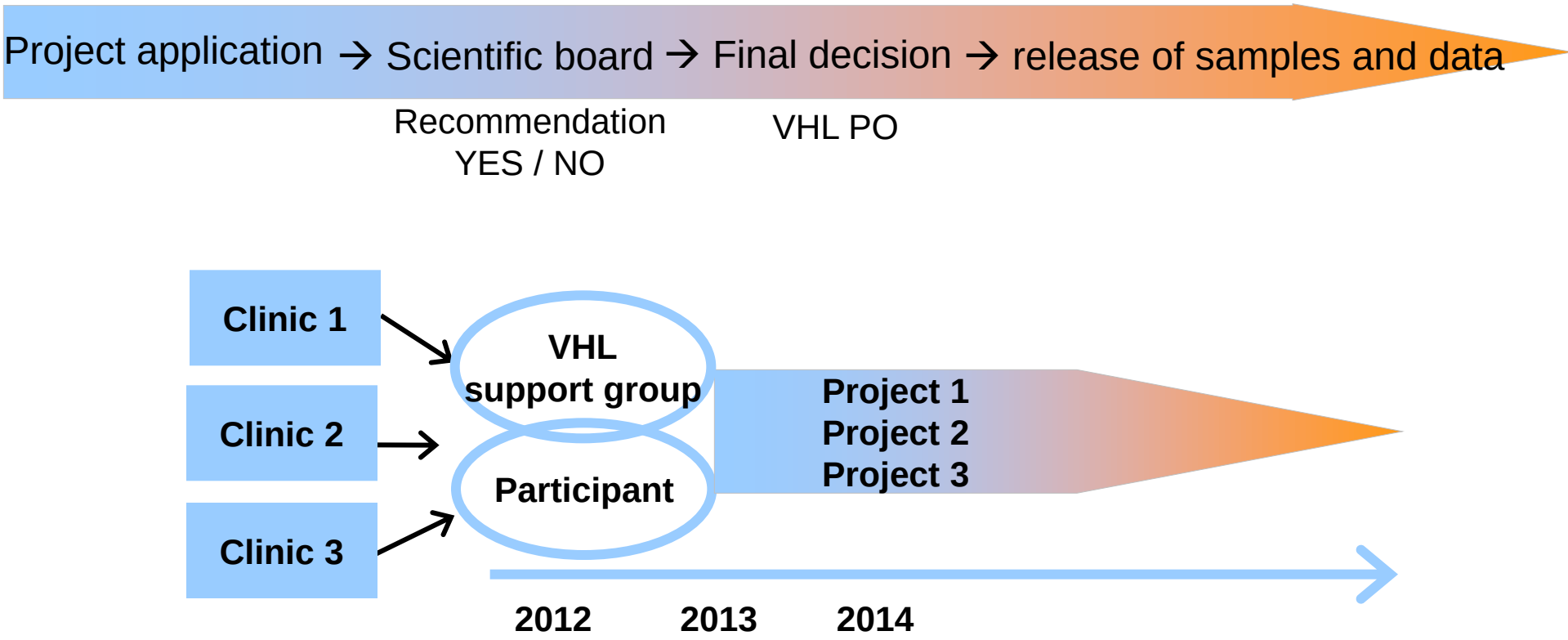
Medical Data entered web-based

by participant (pseudonymized)

Review/Validation from a physician

Annually revised

Research projects

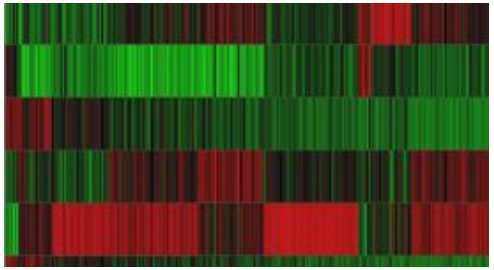


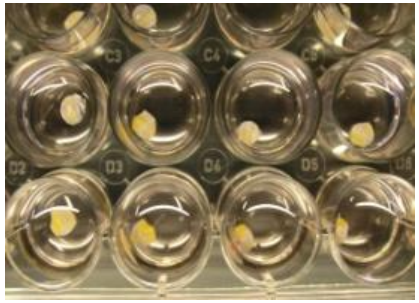
Members of the scientific board of the VHL PO:

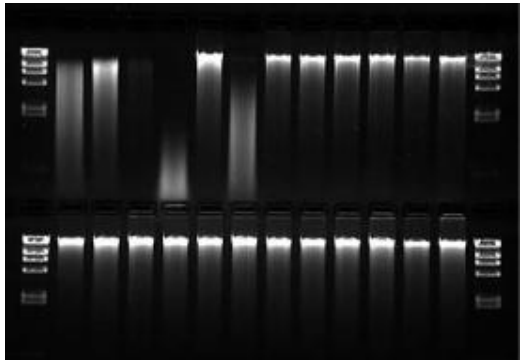
Prof. J. Decker
Prof. H. Brauch
…

Research Results

Research results should be available for the community (public and scientific)







Hope:
Benefit for the individual

VHL Biobank – Present Situation

Ethical vote

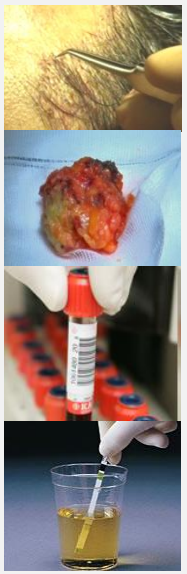
Start of recruitement

25 participants

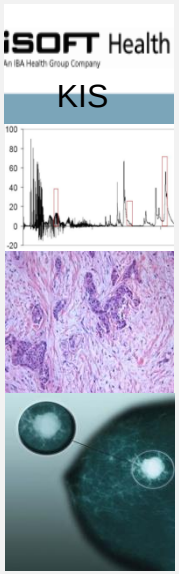
50 participants

100 participants

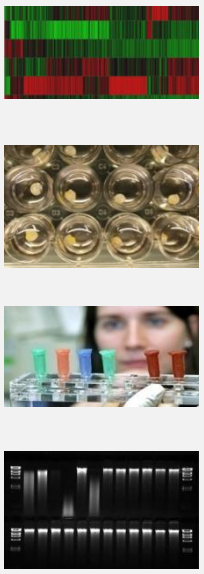
08/2011 **01/2012** **05/2012** **01/2013** **01/2014**



biomaterials

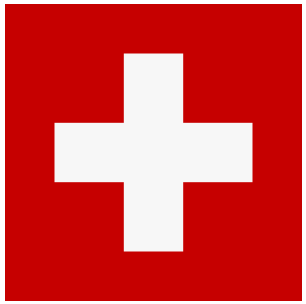


clinical data



research projects

Future perspective



→ Other VHL groups will join our biobank

Thank you for your attention!