



8th International Research Conference on  
Adolescents and Adults with FASD  
**Review, Respond and Relate**

Vancouver , BC, Canada  
April 18 - 21, 2018

**EVERYDAY LIFE AND FASD**  
**A Weekend Break for Adults**  
**Affected by FASD**

**Peer-to-Peer Exchange, Led**  
**by Professionals**

**FASD Deutschland e.V.**

# Background

- **Dramatic increase in the number of adults diagnosed with FASD seeking help from our organisation**
  - **left alone, isolated, ignored, forgotten**
  - **fallen through the cracks**
- **Need for support (peer-to-peer exchange, coaching and/or mentoring)**

# Can We Help? How?

- Decision: Board meeting Summer 2015  
Organise a weekend break for adults with FASD and their immediate caregiver
- Hurdles:
  - ▶ Sponsor required
  - ▶ Location?

# First Steps

- **Applications for grants**
- **Develop concept**
- **Find the right professionals**
- **Find a suitable location**
- **Spread information**

# First Achievements

## 29 people

- First event of this type: July 2016, Fulda youth hostel
- Sponsor = health insurance company



- 15 adults diagnosed with FASD  
20 - 58 years old
- 6 caregivers/life partners,  
4 children, 1 childminder
- 1 social worker (FASD experienced)
- 2 other experienced speakers

# Key Questions

First Weekend Break  
for Adults  
15 - 17 July 2016

- **Moderated Discussion "Life Circumstances"**  
(led by social worker)
  - What can or can't I manage well?
  - Where/when do I need help?
  - How can we help each other?
  - What do we need?

# First Results

First Weekend Break  
for Adults  
15 - 17 July 2016

- **Mission Statement: "First and foremost we want justice ..."**
  - Clarify the legal status of the unborn child (person)
  - Ask to be respected and to be met at eye level
  - Demand of us, we act NOW.
- **Questionnaire about medical conditions developed**  
(similar to the beginnings of "The Lay of the Land")
- **First adult FASD self-help group, Berlin**

- **Overall positive response**
  - **request for a repeat weekend 2017**
  - **one extra day**
  - **focus on "Emergency Plans" and "FASD pass"**



# Second Event

26 - 29 July 2017

60 people

- **26 adults with FASD; 15 caregivers/life partners**
- **4 speakers plus 1 moderator**
- **12 children and 2 childminders**
  - **2 FASD groups: "high-functioning/"low-functioning"**
  - **group for caregivers/life partners**  
(own moderator)
  - **additional accommodation booked**
  - **costs: € 12,700 incl. travel expenses (DAK)**

# Group Rules

- **Secrecy**                      **Nothing said here leaves this room**
- **Voluntariness**              **Only tell as much as you feel happy to**
- **Value**                              **No judgement of what others say**
- **Interaction**                      **Be respectful, hear others out**
- **Questions**                      **Dealt with in order of priority**

# Subjects of Discussion

## Key words:

- Household
  - Dealing with the authorities
  - Family planning
  - Help with daily routine
- Work (incl. sheltered workplace)
  - Living accommodation
  - Legal issues \*
  - Pensions
- \* People with FASD don't qualify for compensation under the German OEG (Victims' Compensation Statute)

## Individuals with FASD

- realised potential to help each other
- improved confidence (self-esteem)
- developed a feeling of "belonging"

## Caregivers/Partners

- recognized need for "road maps"  
"What do I do if/when ...?"
- first ideas put together
  - unique
  - simple
  - practiced
  - updated

**"A trouble shared is a trouble halved"**

## ► Conclusions

### We need:

- knowledge/awareness about FASD; how adult lives are affected
- practical help
- political awareness/readiness > legislation

### We have:

- a wealth of knowledge and experience
- courage to stand up and be counted

**We're worth it!!!**

## Goodbye and auf Wiedersehen!



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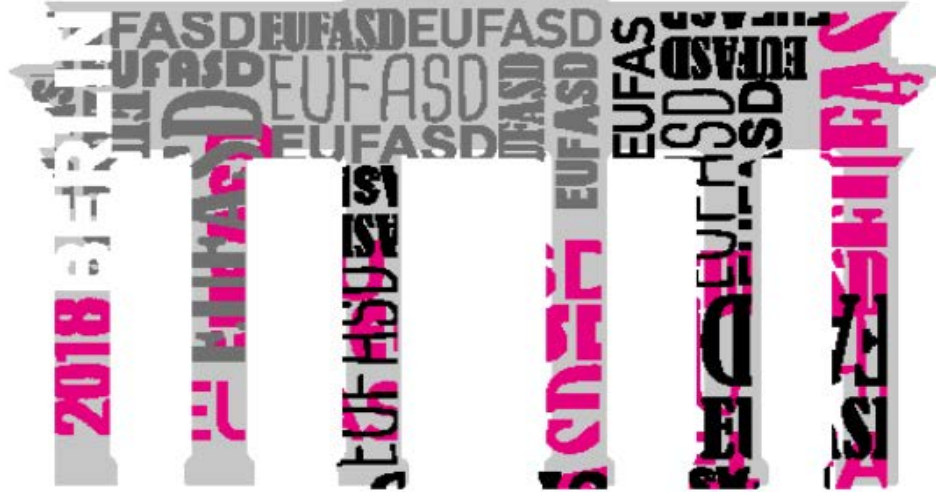
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European Conference  
Fetal Alcohol Spectrum Disorders



**EUFASD 2018**  
**24 - 26 September**

**H4 Hotel Berlin**  
**Alexanderplatz**  
**(formerly Ramada)**

**EUROPEAN**  
**FASD**  
**ALLIANCE**