

Eva Luise Köhler Research Prize for Rare Diseases

1st European Rare Disease Day
2008 Feb. 29th, Berlin, Germany



Mrs. Köhler and Laureates



Dr. Stephen Groft, ORD



with the Minister of Health



Eva Luise and Horst Köhler Foundation (award sponsors)



Attending Presidents and First Ladies



- print
- news agencies
- internet
- TV
- video text
- radio

> 300 media reports

... and perpetuating

Reporting “Pyramide“ (Frequency) since Rare Disease Day 2008

Solution
Domain

RD research
cutting edge
of science,
models for other diseases

Portrait of an orphan drug

Orphan drugs – since EU regulation 44

Patient organizations exist, ACHSE as umbrella

Problem
Domain

Research needed - but not profitable to develop drugs

EU-Definition of a RD, ~ 4 Million in Germany affected, > 6000 RDs

Portrait of an individual patient's story / disease