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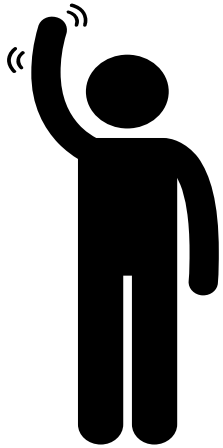
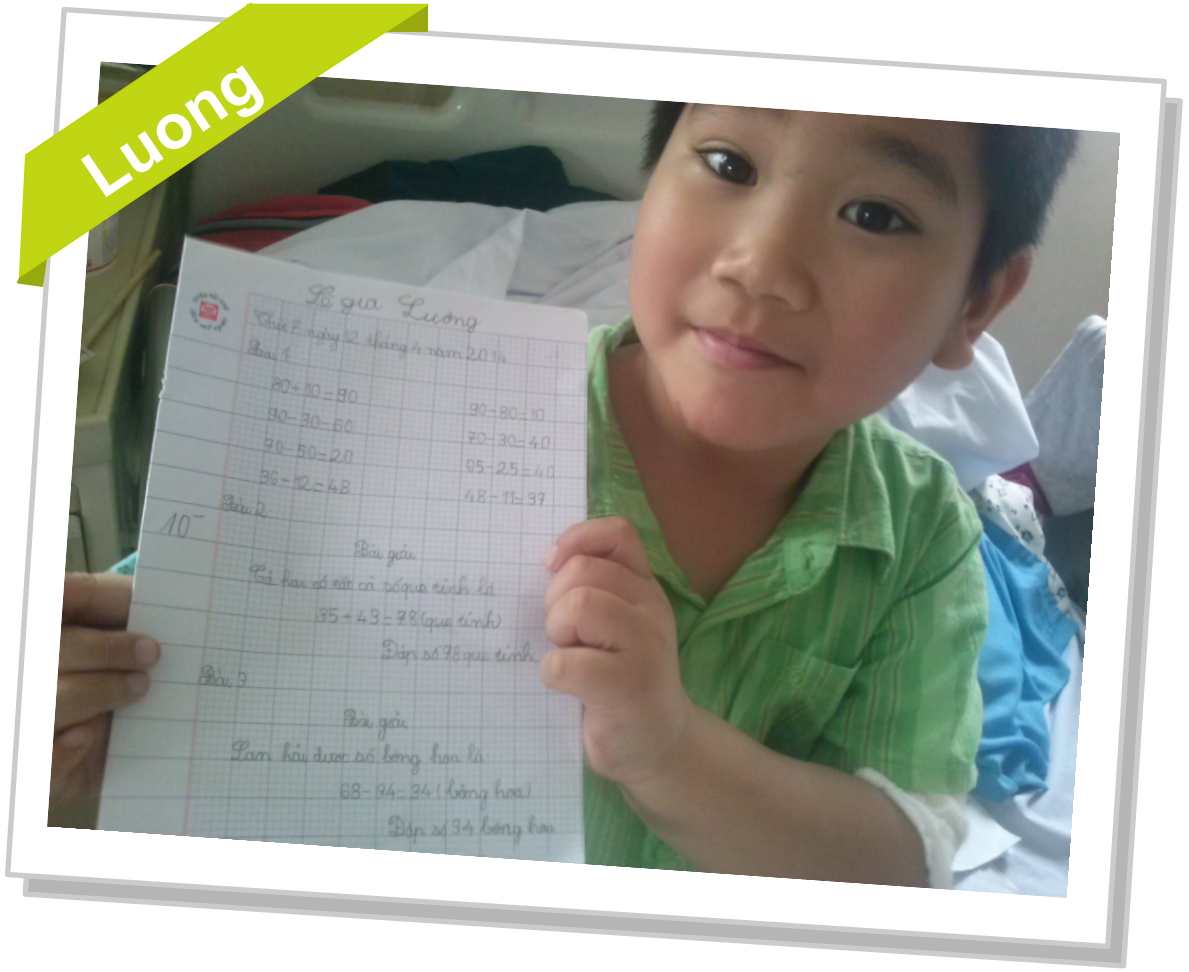
Focus on rare diseases and uncommon cancers

Jonathan Morton

MedComms Networking Event,
Oxford, 3 August 2016

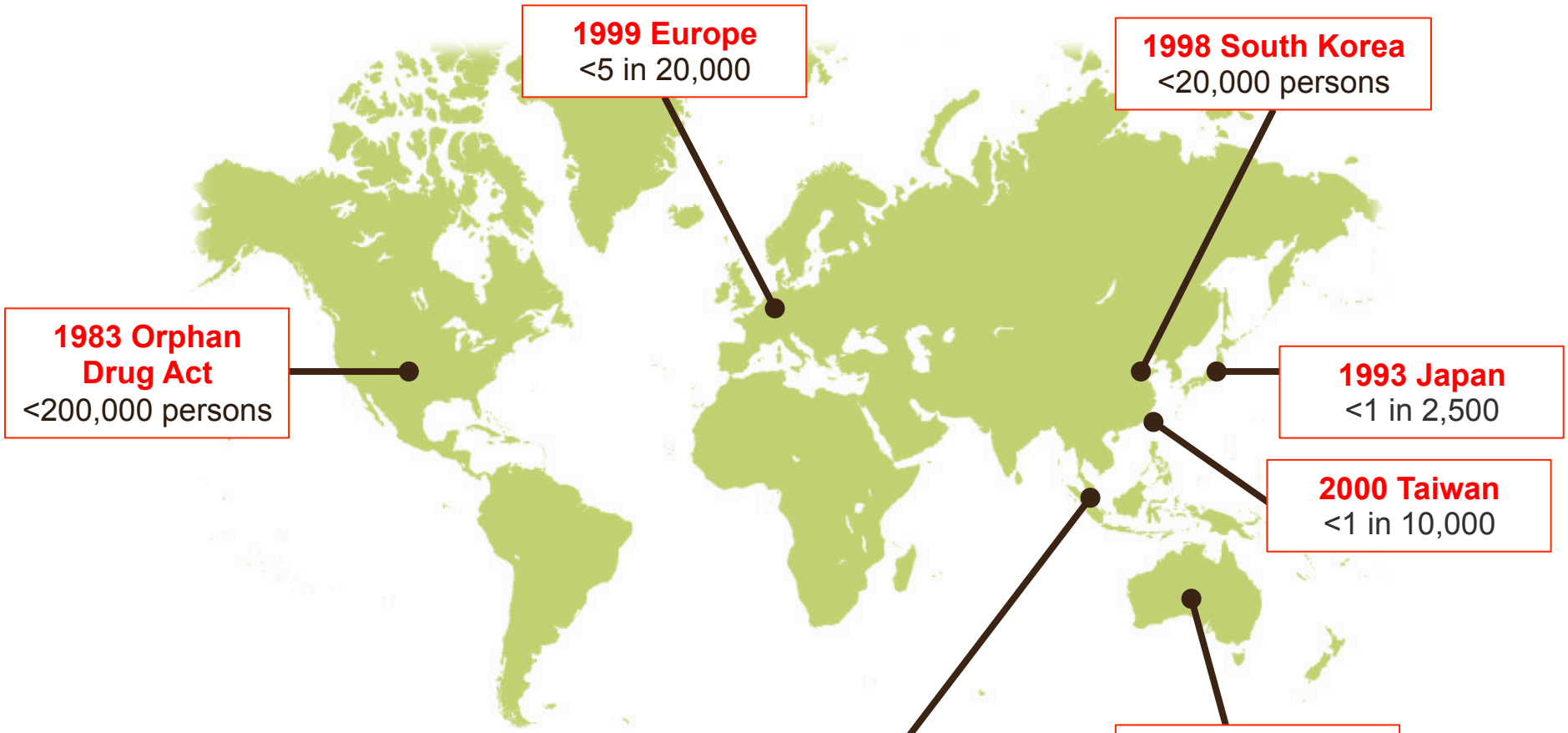
Meet Luong





What is a rare disease?

The orphan drug revolution



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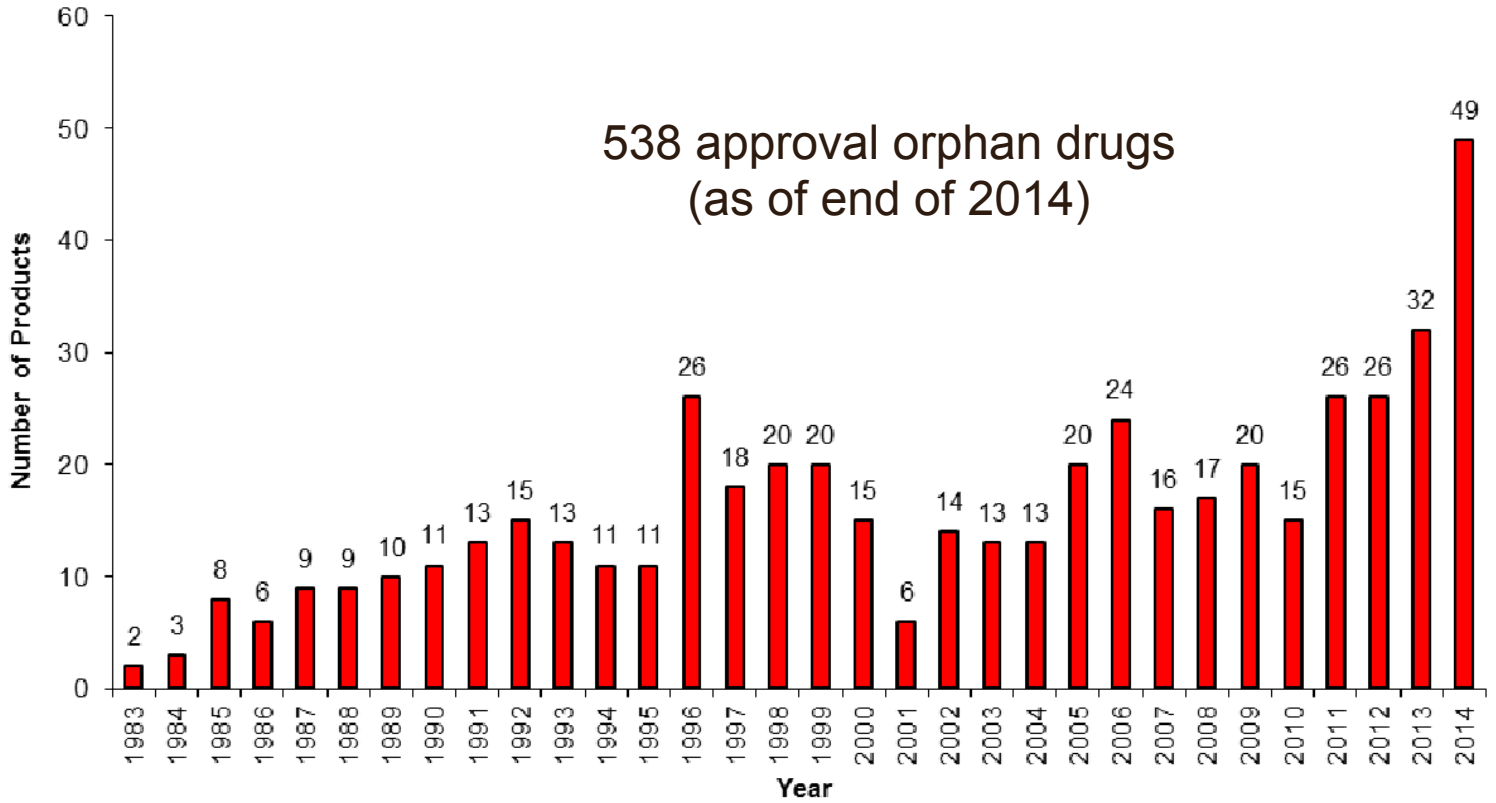
Orphan drug approvals in the USA



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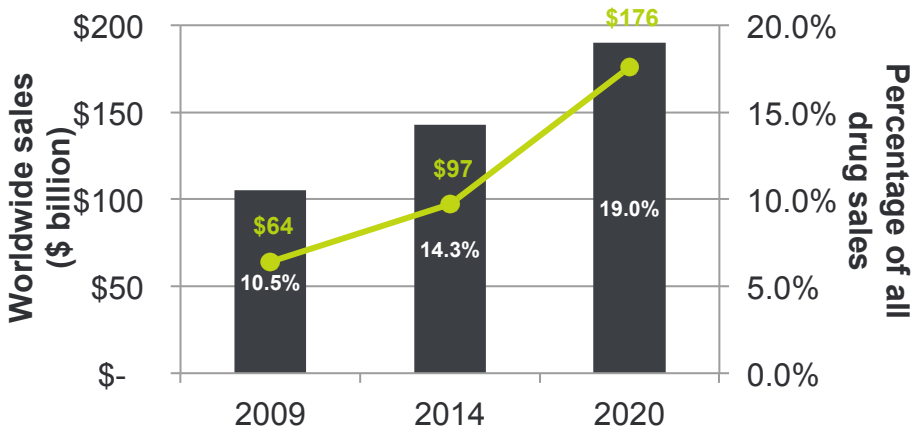
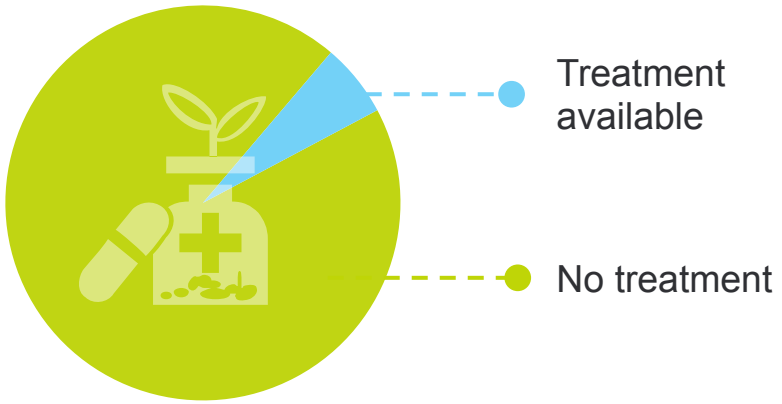
http://www.fdalawblog.net/fda_law_blog_hyman_phelps/2015/02/the-2014-numbers-are-in-fdas-orphan-drug-program-shatters-records.html (accessed 2 August 2016)

Rare diseases: the numbers

Fastest growing sector of the biopharmaceutical industry[1]



There are thought to be approximately 7000 rare diseases[2]



If all the people in the world with rare diseases lived in one country, it would be the world's third most populous country[2]

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1. Evaluate Pharma-orphan Drug Report 2014: http://info.evaluategroup.com/rs/evaluatepharmaltd/images/2014OD.pdf
2. Global genes.org/rare-diseases-facts-statistics/

Challenges in orphan drug development

- Complex pathologies, with poorly defined natural history
- Difficulty identifying patients
- Small pools of experts
- Lack of awareness and political support
- Uncertainty amongst regulators
- Barriers to patient access

Forging a career in rare disease medical communications

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CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD
June 2003
BSc Pharmacology
September 2006
PhD Medical biochemistry
October 2006
Started career as a medical writer
November 2008
Senior medical writer
May 2010
Communications consultant
July 2012
Founded rare disease practice
January 2013
Communications director
March 2015
Agency lead, Comradis

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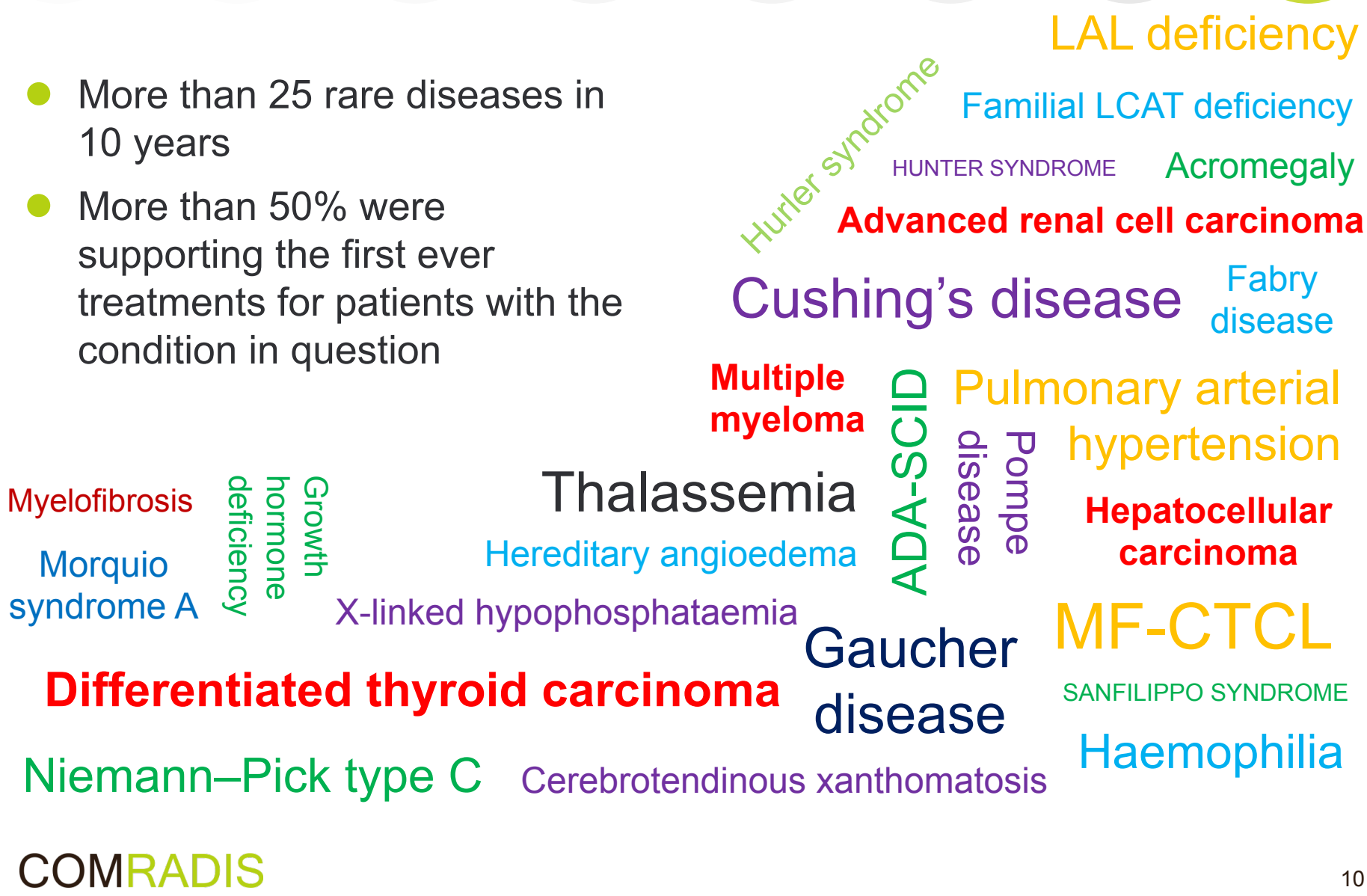
Variety is the spice of life…

- More than 25 rare diseases in 10 years
- More than 50% were supporting the first ever treatments for patients with the condition in question



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So where does Comradis fit in?

Comradis was created in 2013 to help tackle the persistent challenges facing the rare disease community

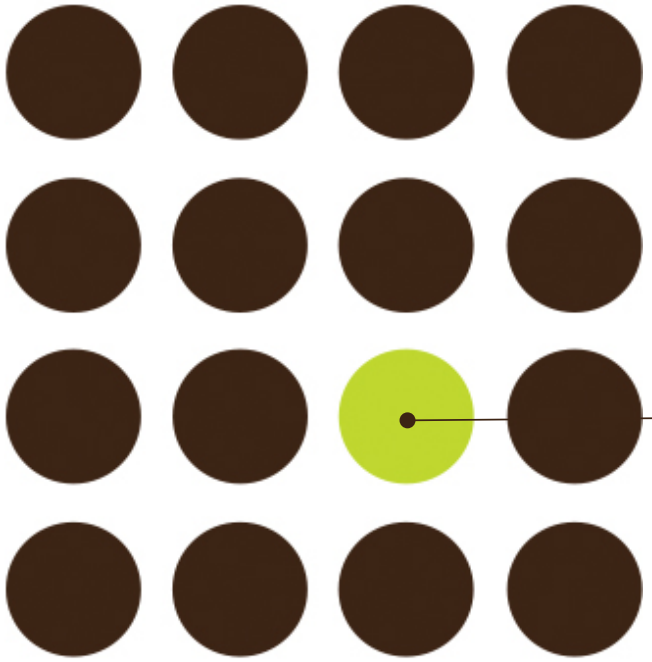
More prompt diagnosis

Better treatments

Access for all

Ultimately, we aim to improve standards of care for those affected by rare diseases and uncommon cancers

Com-what?



- Approximately 1 in 16 people will suffer from a rare disease at some point during their lifetime
- We focus exclusively on rare diseases and uncommon cancers
- Our key areas of differentiation:
  - Communications
  - Commercialization
  - Communities

Re-evaluating rare disease communications

> ***"Everything that can be invented has been invented"***

Charles H Duell
Commissioner of US Patent Office, 1899

Facilitating commercialization through industry-leading insights

Complex pathologies, with poorly defined natural history	Identify, evaluate and enhance sources of natural history data
Difficulty identifying patients	Patient-identification strategies
Small pools of experts	Stakeholder identification and mapping of current treatment practices
Lack of awareness and political support	Mapping of political and legislative environment
Uncertainty amongst regulators	Identification and evaluation of potential endpoint and precedents
Barriers to patient access	Mapping of patient access pathways

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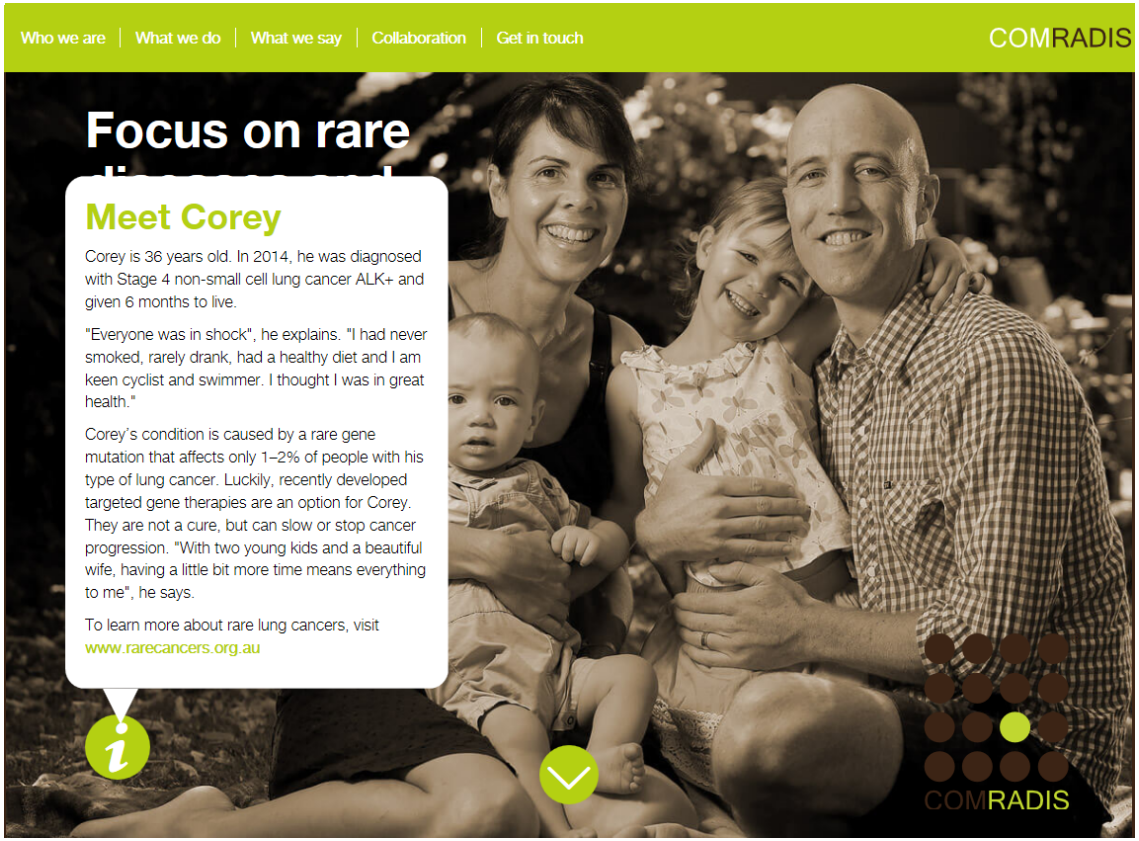
Part of the disease community

Part of the disease community



rare cancers AUSTRALIA

CNETS Carcinoid NeuroEndocrine Tumor Society (Singapore)

Rainbow Across Borders

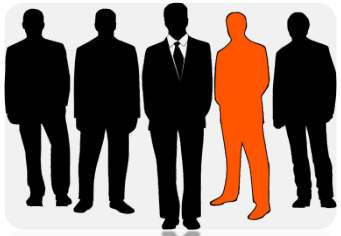
findacure

MPS support research awareness Wicked GENES

TIF Thalassaemia International Federation

A few recent projects...

Patient interviews



Patient advocacy consultancy

Stakeholder mapping

Portfolio planning

Regulatory submissions

Supporting non-profit organizations

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Thoughts from a newbie

- What attracted me to Comradis?
  - I wanted to make a positive impact on the lives of patients who need support the most!
  - I was expecting to be given a lot of responsibilities from the start
  - I wanted to keep learning about rare diseases and work on a diverse range of projects ranging from consulting to medical content development

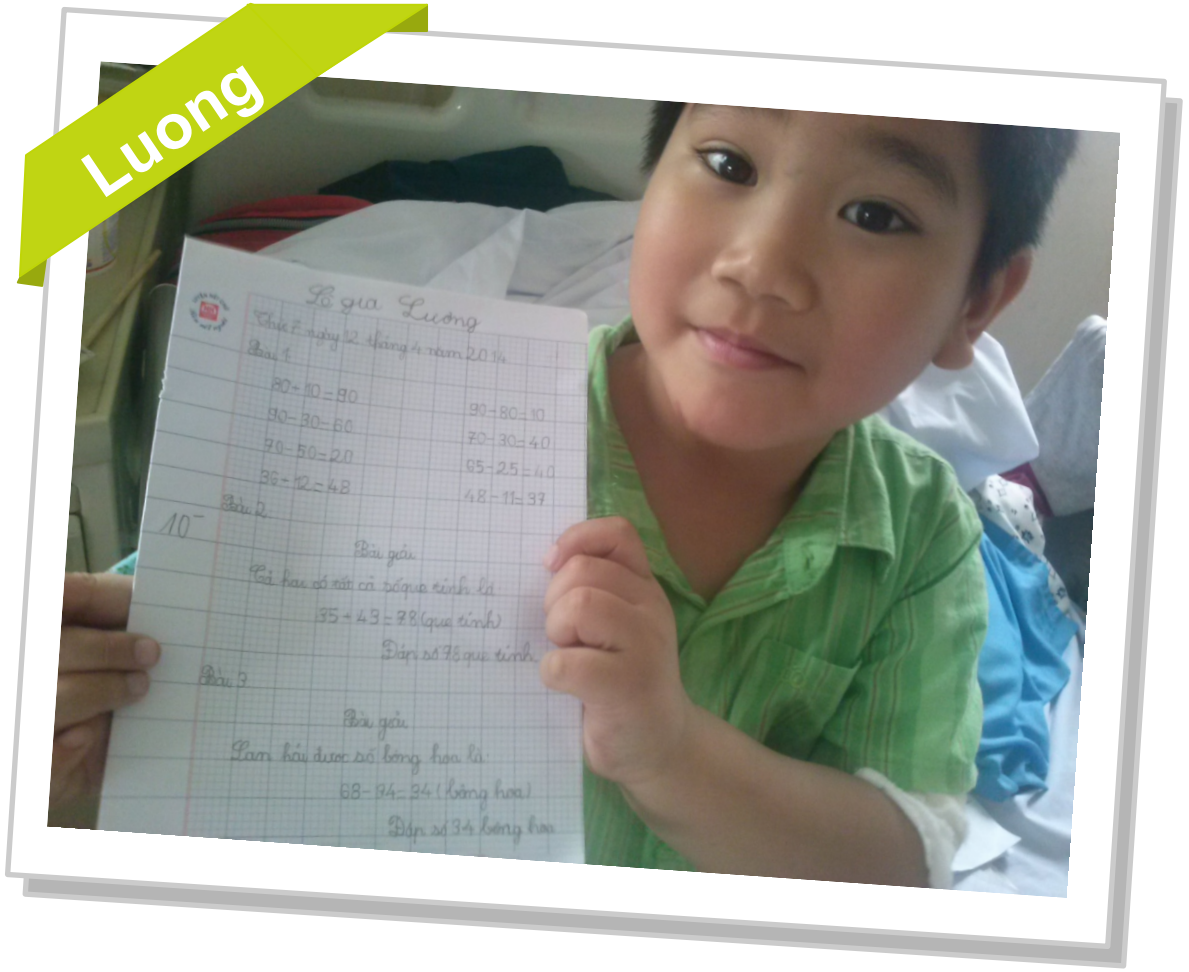
- Were all of these expectations met? **YES!!!**

- What skills are relevant to my role?
  - Analyzing scientific data and having a good eye for detail
  - Writing to the highest standard
  - Having good communication skills

Alicja Busiewicz

A final thought...

> Go into the world and do well; but more importantly, go into the world and do good
>
> *Minor Myers, Jr*



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Thank you

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