



Association Francophone des Glycogénoses

Philip Maes, AFG President

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**The association
Strategic Direction**

AFG : general info

- 210 member families
- 160 patients
- Scientific Council : 13 specialists, presided by Pr. P. Labrune
- Dedicated workgroups for T II, III and V.
- Administrative Council : 6 ACTIVE members, next year 8 members ...
- French speaking – but international orientation (members from 10 countries)

The administrative council



De gauche à droite:
Florence Faure, secrétaire
Philip Maes, président
Stéphane Laderrière,
conseiller informatique
Quentin Ruby, candidat
Valérie Mahé, trésor. Adj.
Eric Dupont, secr. Adj.
Alain Bichat, candidat
Claude Guiraud, trésorier

The goals of the AFG

(And possibly of all GSD related associations)

Statutory

- humanitarian assistance to all persons affected by GSD
- break their isolation
- share relevant information
- provide them and their families help and support

Implicit

The reason to be is the disease, hence stimulating ways to combat this disease on all levels:

- Medical
- Research
- Dietary

How to pursue the statutory goals in the long run?
What strategies to fight the disease?
How resolve conflict of interest between both goals?

The AFG year 2020

- Healing the disease will have side-effects for our associations:
 - Loss of critical mass
 - Loss of financial means
 - Members become more isolated
 - Disinterest for the rarest forms



The bad exemple: « la Meduse » the flagship of the French Navy, failed at 160 km from its goal

Strategic Priorities

- Healing the disease will have side-effects for our associations:
 - Loss of critical mass
 - Loss of financial means
 - Members become more isolated
 - Disinterest for the rarest forms

- Healing remains one of our goals, but we need to care about :
- Better represent all forms, even the very rare ones.
 - Regroup int'ly the very rare forms, so they gain critical mass
 - Keep statutory goals in focus
 - Avoid exhausting our financial means on research, but keep stimulating research



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International expectations

- Together, we can do more to achieve our goals:
 - Communication
 - Common information, workgroup interworking
 - Network of GSD associations: keep it going – even without a formal structure.
 - Scientifical
 - Our hope : make progress together, leverage as a worldwide community.



Thank You!



- *AlG Italy for organising this event*
- *For participating*
- *Constructive discussions that have made this event become WorldWide!*

