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# Album photo

Journée Maladies Rares

26 février 2025

Salle des fêtes de Gentilly - Nancy

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*Crédit photos : Khaled FRIKHA (www.kfrikha.com)*

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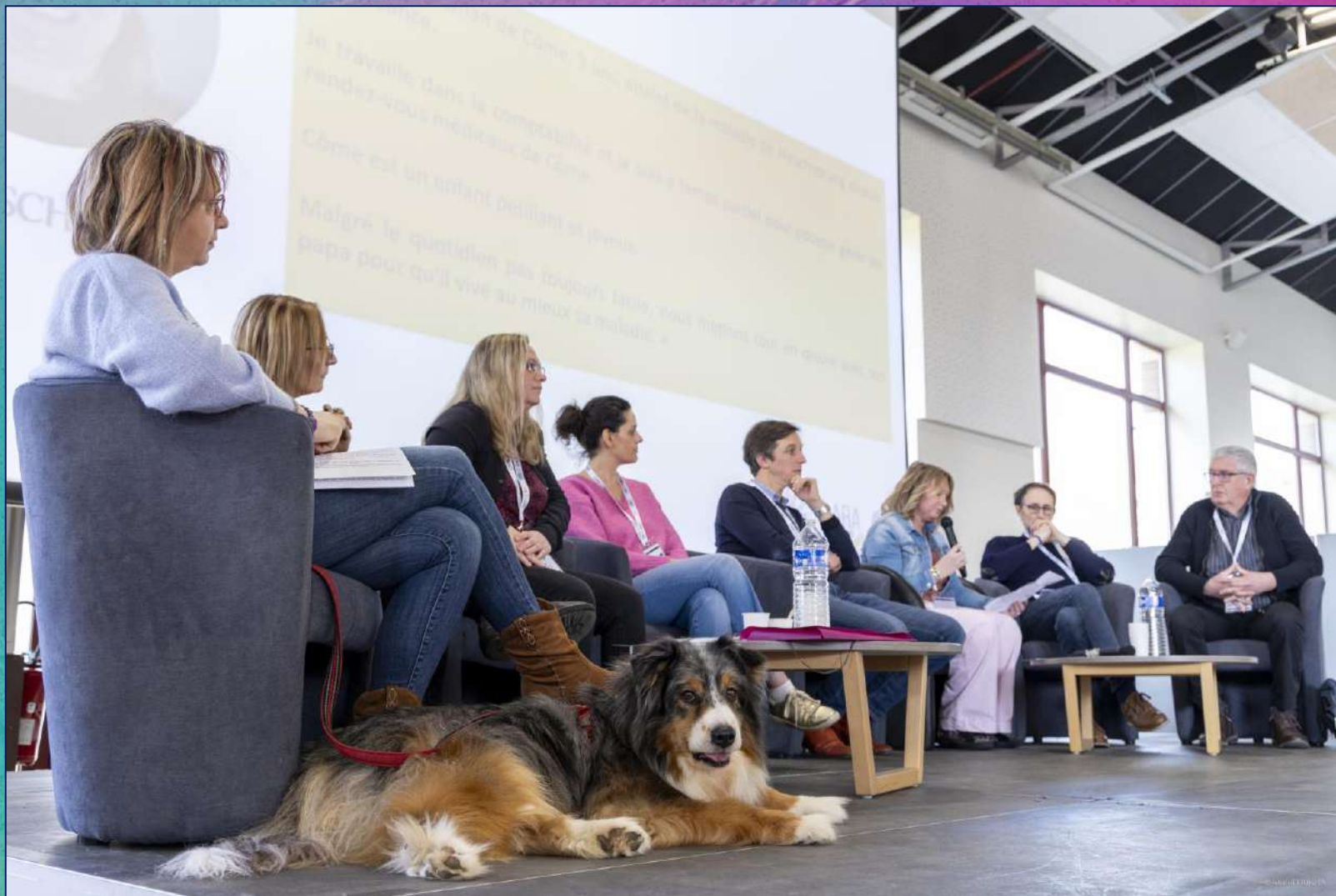
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## LES VOLONTAIRES EN SERVICE CIVIQUE

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- Les volontaires sont âgés de 16 à 25 ans (30 ans si en situation de handicap)
- Durée de 6 à 18 mois (3 mois au CHRU) avec un stage sur l'année
- Un seul critère de recrutement : la MOTIVATION
- Nécessité d'un tuteur formé (rôle d'accompagnement dans le projet d'avenir)
- Diverses formations proposées : PSC1, hygiène et sécurité-vigilance, formations civiques et citoyennes, sensibilisation aux handicaps (formations théoriques et stages d'immersion en EBMG)

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VOUS AVEZ DES  
DIFFICULTÉS  
POUR  
VOUS  
SOIGNER ?



UN CONSEILLER  
ACCOMPAGNEMENT SANTÉ  
EST LÀ POUR VOUS.



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## 2 Informer, former et sensibiliser aux maladies rares :

- Former les professionnels de ville : formation des DAC de Lorraine en 2024 en lien avec l'ARS Grand Est et Maladies Rares Occitanie.



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## DES MALADIES RARES PAS SI RARES QUE ÇA !

Andi-Rare, BRAIN-TEAM, CARDIOGEN,  
DEFIScience, FAJER, FAYE-Multi, FILFOIE, FILNEMUS,  
FILSLAN, FIMARAD, FIMATHO, FIBENDO, GDM,  
MARIH, McGRE, MHémo, Mura/CFTR, NeuroSphere,  
ORIKO, OSCAR, RespiFIL, SENGSENE, TETECOU  
[www.maladiesraresinfo.org](http://www.maladiesraresinfo.org)



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**Maladie de Rendu-Osler / HHT**

Plus qu'un saignement de nez ...

... une dérégulation de l'angiogenèse.

Symptômes visibles,

Spontanées Récidivantes

Anémiantes **Epistaxis** Irrégulières

Télangiectasies peau & muqueuses

Malformations artério-veineuses poumons, foie, cerveau, tube digestif

... handicap invisible.

MALADIE GÉNÉTIQUE RARE

**AMRO-HHT-France,**  
bien plus qu'une association de patients

- Soutenir, conseiller, représenter** les malades et leurs familles
- Informier** des traitements et des progrès de la science
- Financer** la recherche médicale grâce aux adhésions et dons
- Etre en lien** avec le réseau médical
- Développer** l'Education Thérapeutique du Patient (ETP)

**AMRO-HHT-France, c'est aussi :**

- Application Rose (Suivi épistaxis)
- Journée Information Médicale
- Groupes de parole
- Rencontres régionales

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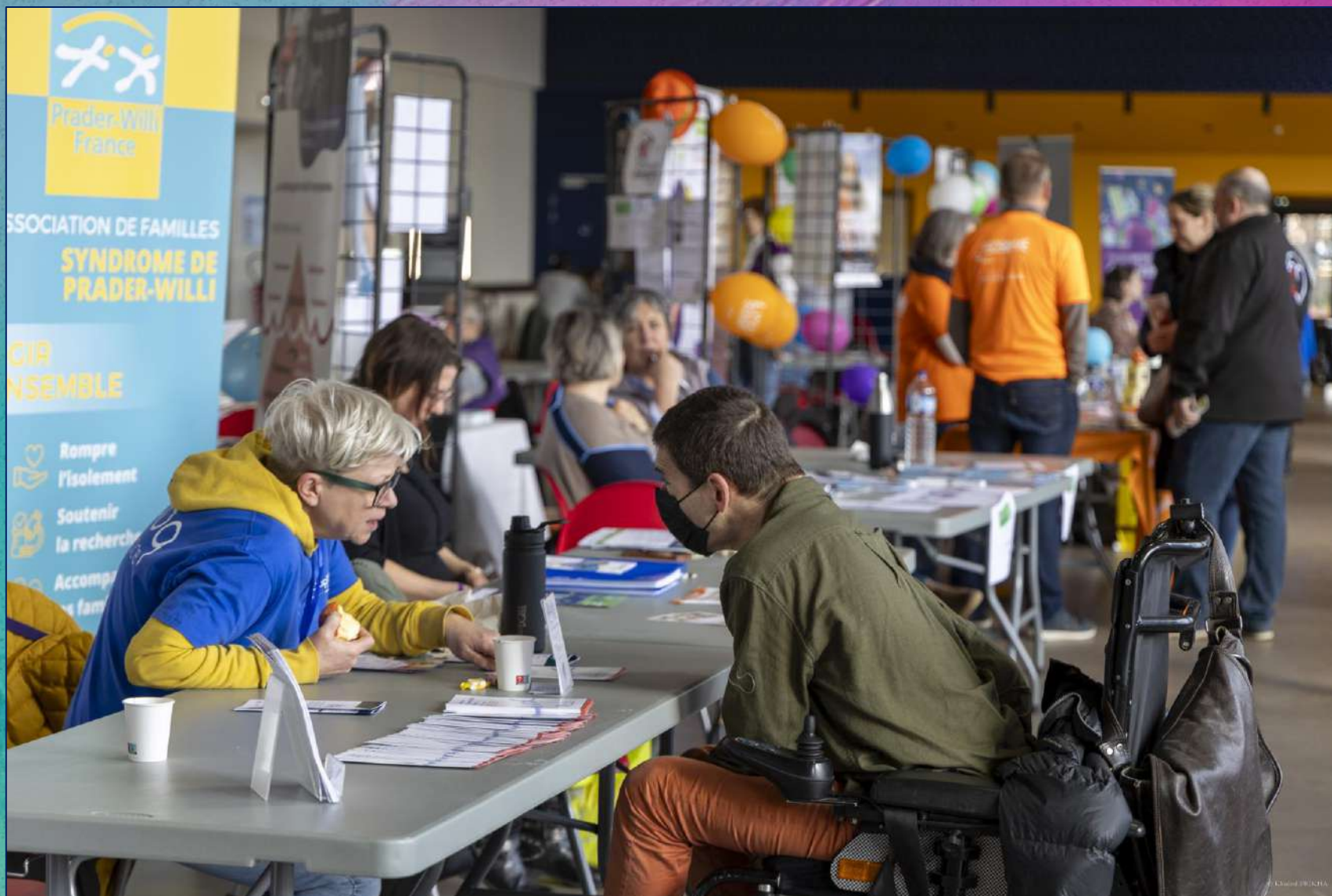


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vos couleurs  
avec nous ! 😊

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