



Association GRANDIR (France)

Created more than 40 years ago, the GRANDIR association informs, helps and advises parents of children with growth problems but also anyone suffering from a rare growth disorder and/or treated with growth hormone.

An illustrated non-exhaustive list of our recent Growth Awareness actions

1. Growth Awareness Week

In collaboration with the ICOSEP, scientific societies and several pharmaceutical companies the Grandir Association relayed many messages, pictures and videos via different social media (Facebook, LinkedIN, Web site,...) during the “2024 Growth Awareness Week”.

“Today, September 20, is World “CHILD GROWTH AWARENESS” Day. “

Growth has a social and aesthetic character but is above all a major sign of overall health. It is essential to make the diagnosis in time thanks to good monitoring of the growth curve, allowing if necessary to treat effectively with growth hormone, which moreover does much more than act on growth.

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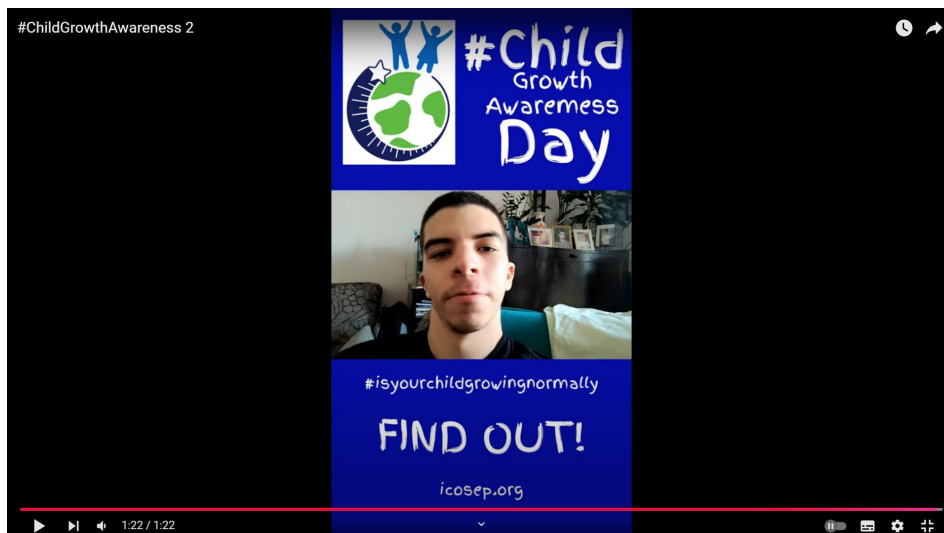
Children have little time to grow up, but a lifetime to live with the consequences. Their growth is a major sign of their overall health. It is therefore essential to make the diagnosis in time.

The Grandir Association provides support in more than 20 growth-related pathologies and the International Coalition of Organizations Supporting Endocrine Patients (ICOSEP) brings together associations from more than 35 countries.

Follow, "like 👍" and share the Association Grandir campaign during the week of September 15 to 21.

There is still a long way to go...

Shared ICOSEP video



<https://youtu.be/vGoLRaylCEs?si=O4s0f15bvddiLro>

A special attention was paid to girls coping with growth problems, via a short video produced by Novo Nordisk in partnership with GRANDIR.

“Being a girl doesn't necessarily mean being small. However, we are more worried about the small size of a boy than that of a girl.”

https://youtu.be/Re-qeSht_4s



Other shared NOVO NORDISK videos on:

“The questions....” <https://vimeo.com/916670686/0da961ded0?share=copy>

“The growth measurements” <https://vimeo.com/916678556/92ed144fe0?share=copy>

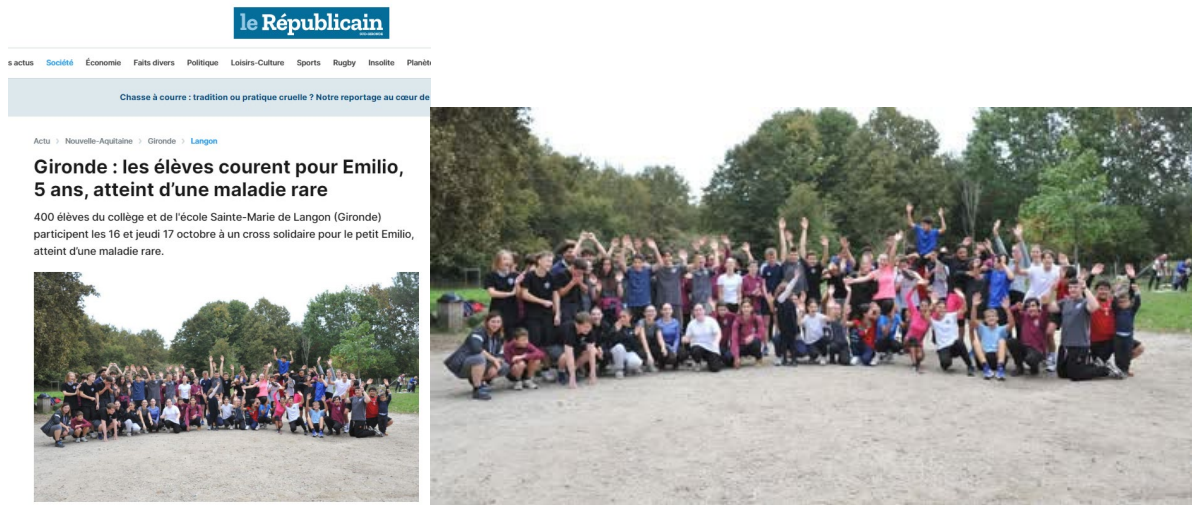
2. CHARITY FUNDRAISING EVENTS

Local charity fundraising activities and evenings are organized by Grandir members, like the activities organized by the parents of the 5-yr old Emilio, suffering from a rare endocrine disease. Profits were donated to the GRANDIR association and relayed in the local press.

Special evening event organized by Orel Du and supported by the **Avenir Pailleton Handball team** (Gironde) which resulted in a donation of 2000 euros to the Grandir Association.



The solidarity cross by the students of the **Sainte Marie college in Langon (Gironde)**: a great action for the benefit of the Grandir Association, that was related in the local press “Le Républicain”.



In Montpellier, the raffle organized during the **Mid-Autumn Festival of the Franco-Vietnamese “Vân Nam Association”** resulted in a 500 Eur donation for the Grandir Association to Peter Coopman.



Fondation SNCF, Les « Coups de Cœur Citoyens » 2024



Grandir also received a 1000 Eur financial support from the French SNCF railway foundation, thanks to our regional representative Magali Bourgaux.



3. CHILDREN'S CAMP/COLONY ORGANIZATION:

It is thanks to the significant financial support of the "Fondation de France" with the #capouvert program that the Grandir association was able to organize this fall once again a camp for children treated with growth hormone. Great activities were organized by our service provider "Temps Jeunes" in a magnificent setting in Saint-Nectaire (Auvergne), with adapted organization. Thanks to Nathalie Ferard for her continued involvement in this very popular and successful activity.



4. GIVING TUESDAY

After the Black Friday and Cyber Monday, the Grandir Association organized this year again its annual "Giving Tuesday campaign" on December 3rd, an action that is still going on until December 31st.

There's a very attractive first price: **1 night in a Family LodgeBoat for 4 people in Gruissan**, obtained thanks to a generous sponsor.



5. PARTICIPATION AT MEDICAL MEETINGS:

Members of the Grandir board are actively participating at local medical meetings as well as international congresses: some examples:

Patient meeting organized by the **HYPO Center in Marseille AP-HM Center for rare pituitary diseases:**

"How can we best live with or support a loved one with a pituitary disease? From the youngest to the oldest » (Marseille, December 2024) with the active implication of Elisabeth Chodorge.



Catherine Houziaux participated and represented Grandir at the **European Society For Paediatric Endocrinology (ESPE)** meeting in Liverpool.



Our president Béatrice Demaret and vice-president Nathalie Ferard, participated at the **national congress of the “Société Française d'Endocrinologie”** at Clermont-Ferrand (Auvergne). Meetings and fruitful exchanges with representatives of the Reference and Competence Centers, with the Firendo “Filière Maladies Rares Endocriniennes”, with pharmaceutical laboratories. Interesting conferences, new developments...





Our vice-président Nathalie Ferard participated at the **General Assembly of the Endo ERN** organization in Milan (Italy), and joined as ePAG Chair the MTG5 group on **“Growth and genetic obesity syndroms”**



L'Assemblée générale d'Endo ERN

De nouveaux animateurs pour le groupe MTG5 Endo ERN « Growth and genetic obesity syndroms »

A l'occasion de l'Assemblée Générale Endo ERN à Milan, de nouveaux présidents du groupe MTG5 «Growth and genetic obesity syndroms» ont été présentés. Je remercie chaleureusement le professeur Irène Netchine et le professeur Gudmundur Johannsson, qui présidaient ce groupe jusqu'en avril. C'était très agréable de partager avec eux.

Félicitations au Pr Susan O'Connell et au Pr Charlotte Hoybye, qui poursuivent ce travail d'animation en reprenant la co-présidence de ce groupe. Je suis très heureuse d'être à leurs côtés en tant que représentante de patients. L'expertise de ces spécialistes, leur motivation et engagement à partager leurs compétences au niveau européen au sein d'Endo ERN avec d'autres professionnels de santé, est remarquable.

Nathalie Ferard



6. FAMILY VIDEOCONFERENCE MEETINGS

Regular videoconference exchanges are organized to discuss either childhood or adult growth hormone issues.



7. PARTICIPATION AT THE THE PARALYMPIC GAMES #PARIS2024:

Thanks to the “Alliance Maladies Rares” a limited number of Grandir members received tickets to participate at the **PARALYMPIC GAMES #PARIS2024**



8. PODCAST ON INJECTION RITUAL:

The moment of the #growthhormonetreatment injection, a dreaded moment for your child?

Setting up a daily ritual sometimes helps reduce anxiety and make this moment easier and more fluid. In this episode, discover how to establish this ritual to create a peaceful and reassuring atmosphere.

(Developed by Merck in collaboration with the medical team at the Kremlin-Bicêtre hospital in Paris and Grandir)

<https://youtu.be/Jq6hklOwN9E>

9. SUPPORT FOR THE “MISS SMALL BEAUTY” PAYS DE LA LOIRE COMPETITION:

The Grandir Association responded positively to the wish of Mrs Florine Juhel (1,54 m), a young woman who benefited from growth hormone treatment when she was younger. She participated in the “**Miss Small Beauty Pays de la Loire 2024 competition**”, and talked about the Grandir Association. Bravo to Justine (on the right on the picture) who finished “*Deuxième Dauphine*”.



December 2024, For the Grandir Association