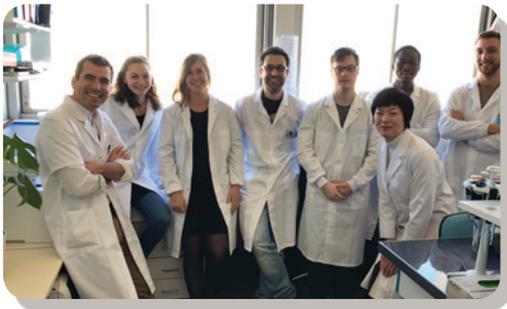




YEAR *in review*

A note from Canaud Lab

Canaud Lab received a \$30,000 research donation from CLOVES Syndrome Community in the past year.



Canaud Lab is dedicated to deciphering the mechanisms that underlie the physiopathology of overgrowth syndromes in order to improve the quality of life of people with CLOVES and PROS. We have been working for many years on the PIK3/AKT/mTOR pathway.

The laboratory is developing new in vitro and in vivo models to better understand disease progression, to identify potential biomarkers and to offer new therapeutic opportunities. To this end, we have engineered multiple genetic mouse models and we are using innovative technology to explore the molecular and structural cellular changes in overgrowth syndromes. Currently, we are trying to understand the impact of PIK3CA mutation on the fate of the different tissues (adipose tissues, bones, vessels). This has been a very exciting few years of discovery. If you want to join or visit us, do not hesitate to contact me.

- PROFESSOR GUILLAUME CANAUD - HOPITAL NECKER ENFANTS MALADES

Working to create a CLOVES Collaborative Research Network

CLOVES Syndrome Community was invited to submit a full application to the Rare As One project through the Chan Zuckerberg Initiative. Rare As One would establish a CLOVES and PROS patient-led research network and will work to strengthen community, build capacity, and promote collaboration for people living with Rare Diseases. Awardees are notified in November of 2019.

Biennial Family Conference at Boston Children's Hospital

"The CLOVES conference was everything I hoped it would be and more. I met a team of brilliant doctors that know more about my condition than anyone ever has in my 50 years of life. I was learning from them for once, rather than trying to explain this disease to them. I loved meeting the children with CLOVES and talking with their parents and telling them about my life. What a phenomenal experience for all of us." - Adult with CLOVES Syndrome

156 PEOPLE ATTENDED OUR 5TH FAMILY CONFERENCE FROM THE USA, CANADA, POLAND & GERMANY

Four Leaf Clovers

With support of an author and illustrator, we created a new book for young children with CLOVES. *Four Leaf Clovers* draws parallels between children with CLOVES Syndrome and those without, focusing on acceptance, inclusion, and diversity. *Four Leaf Clovers* strives to not only illustrate acceptance but to shine a light on some simple ways being different can have its benefits. *Four Leaf Clovers* is truly a story about embracing differences of all kinds.



WE'VE DISPERSED 60 COPIES OF FOUR LEAF CLOVERS IN THE PAST SIX MONTHS

CLOVES Family Camp



"CLOVES family camp is the perfect way to meet and get encouragement from other families. Camp is an easy way to relax, learn and grow. It's a laid-back weekend meant specifically to help families meet and share a little bit of life together." - Mom of a child with CLOVES

NEXT SESSION OF CLOVES FAMILY CAMP IS SCHEDULED FOR JUNE 25-28, 2020

**Chan
Zuckerberg
Initiative**