



**MLC FAMILIES
IT'S TIME TO GET
ORGANIZED!**

WHY?

- TO SUPPORT EACH OTHER
- TO BE UP TO DATE WITH RESEARCH
- TO WORK WITH THE RESEARCHERS
- TO MAKE A DIFFERENCE
- BECAUSE IF WE DO NOT DO IT, NO ONE ELSE WILL!



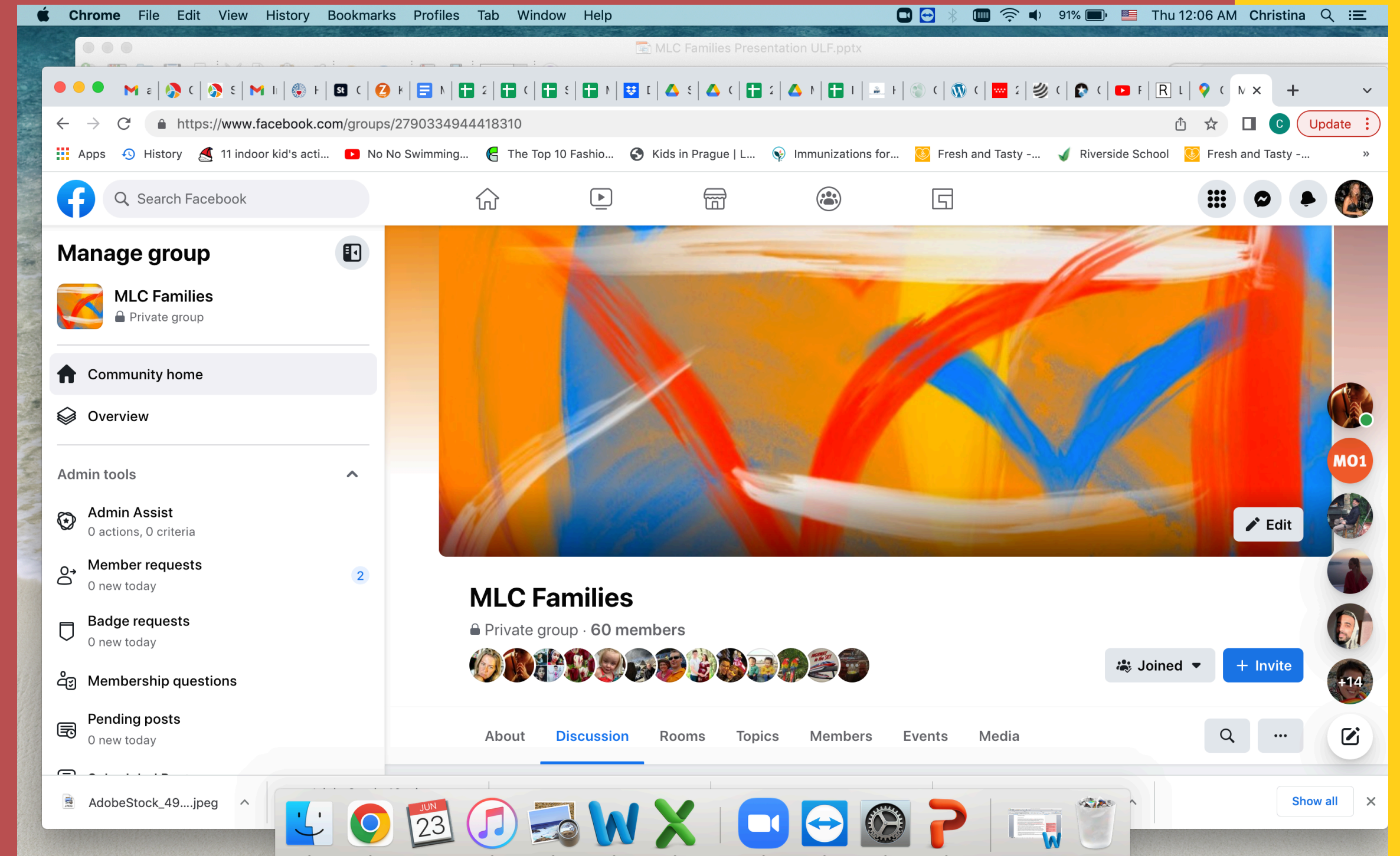
HOW?

1. START A FACEBOOK GROUP
2. ESTABLISH A PARENTS ADVOCACY GROUP
3. ASSIGN COUNTRY AMBASSADORS
4. COLLABORATE WITH RESEARCHERS
5. ORGANIZE CONFERENCES
6. FUNDRAISE



MLC FAMILIES ON FACEBOOK

1. ESTABLISHED ON APRIL 20, 2020
2. CURRENTLY 62 MEMBERS
3. INVALUABLE INFORMATION SHARED
4. REFER FAMILIES AND CREATE A NETWORK



ESTABLISH A PARENTS ADVOCACY (PAG)

1. MLC ALLIANCE - (born on 20/6/2022)
2. UNDER THE AUSPICES OF ULF
3. WWW.MLCALLIANCE.COM (Sept launch)
4. FUNCTIONS
 - Connect with families worldwide
 - Provide resources on doctors, therapies, diet, activities
 - Develop an MLC Alliance Database
 - Organize conferences
 - Fundraise



COUNTRY AMBASSADORS

CANADA

Marla & Ron Chapleau

GREECE

Christina Marouda & Nick Kavelakis

INDIA

Rohit Goyal
Vishal Jhajharia

ITALY

Alessio Giammarioli

JAPAN

Ayako Hiroishi

TURKEY

Pinar Duman



COLLABORATE WITH RESEARCHERS

1. DR. VAN DER KNAAP & RESEARCHERS IN ITALY, SPAIN ETC.

2. MLC ALLIANCE CONTACT DATABASE

- PATIENT NAME
- DOB
- MUTATION
- PHENOTYPE
- CONTACT INFO

3. MLC REGISTRY

- PHD Program in Amsterdam - 300,000 euros



ORGANIZE CONFERENCES

COUNTRY-BASED CONFERENCES

1. USA: ULF CONFERENCE, SUMMER 2023
2. INDIA: FALL 2023
3. TURKEY: WINTER-SPRING 2024



HOW TO GET INVOLVED?

YOU CAN BE AS INVOLVED AS YOU WISH!

1. REFER OTHER FAMILIES TO US
2. BECOME A COUNTRY AMBASSADOR
3. PROVIDE ADMIN SUPPORT TO MLC ALLIANCE
4. HELP US CREATE AND/OR MAINTAIN THE MLC ALLIANCE WEBSITE
5. HELP US ORGANIZE A CONFERENCE OR A FUNDRAISER
6. MAKE A DONATION



MLC ALLIANCE CONTACTS

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