

# **BARTICIPANT** GUIDE

International Children Camp 2024

All information for your stay from July 3rd to July 7th, 2024

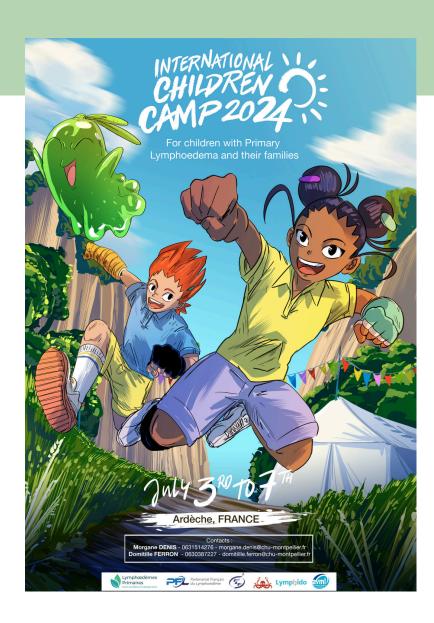
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# Intro

We are delighted to welcome you to the International Children Camp 2024! This guide has been designed to provide you with all the necessary information so that you and your family can prepare and fully enjoy this unforgettable experience.



# presentation

### Chronicles of the International Camp:

Let's go back in time to discover the history of the "International Children Camp," an adventure that began in 2012 in Montpellier and now extends far beyond borders.

In 2012, Professor Isabelle Quéré (CHU Montpellier) and Professor Christine Moffatt (International Lymphoedema Framework) joined forces to create the International Children Camp. Their vision was to create an event where children and adolescents with primary lymphoedema and their families could gather, share experiences, and find support in a space bringing together all stakeholders in primary lymphoedema management.

The first edition brought together ten families from various European countries: France, the United Kingdom, and Sweden. During the camp, linguistic barriers disappeared, giving way to exchanges, sharing, and mutual support.

Building on this initial success, the International Camp expanded to Italy in 2017, thanks to the collaboration of physiotherapist Elodie Stasi and Professor Roccatello from CMID, the Lymphido association, and the Italian Lymphoedema Framework (Italf).

These early editions had a global impact, inspiring the creation of similar programs in the United States ("Watchme" Camp) and Turkey.

#### MISSION

To create an inclusive and caring environment where every participant feels supported, understood, and valued. To achieve this goal, we provide workshops, educational resources, practical tools, and ongoing support to help families face the challenges of lymphoedema.

#### VISION

To build an international community of support and research for individuals affected by primary lymphoedema. With this goal in mind, we aim to raise awareness, educate, and promote best practices in management to improve quality of life, while actively contributing to research advancement.

# 3rd edition

## 3rd Edition International Children Camp:

We are thrilled to present this new edition, returning to France this year, in the beautiful region of Ardèche. This edition promises to be even more exceptional than the previous ones!

We are delighted to welcome around thirty families from 6 different countries: France, Italy, Spain, Ireland, Switzerland, and Germany!

Additionally, we are excited to be joined by experts and representatives from medical and paramedical teams from around the world: France, Italy, England, Ireland, Belgium, Spain, Denmark, Portugal, Poland, and the United States. Their expertise and dedication contribute to making this event a true success.

This third edition promises moments of sharing, support, and learning. We are eager to embark on this adventure with you and continue our commitment to better primary lymphoedema management.

#### CAMP INFORMATION

#### DATES

Wednesday, July 3rd to Sunday, July 7th, 2024

LOCATION

#### **Camping RCN La Bastide**

1, route d'Alès-D111 Sampzon 07120 Ruoms, Ardèche, France Website: <u>RCN La bastide</u>

# Actors & Partners

## Discover the key figures of Camp 2024!

The success of the International Camp is the result of the dedication and support of numerous committed partners in the field of lymphology. Their contribution is essential to make this experience unique for all participants.

Within the team, you will find doctors, lymphotherapist caregivers, and volunteers from a dozen nationalities, all united around the same cause.

# Key Members of the 2024 Edition:



### Prof. Isabelle Quéré (France)

Professor of vascular medicine & lymphology and head of the Reference Center for Rare Diseases - Primary Lymphoedemas (CHU Montpellier). In addition to her research and teaching activities, she initiated international camps for children, working to raise awareness and early treatment of lymphatic diseases among youth.



Specialized lymphology physiotherapist, currently working at CMID (Coordination Center of the Rare Diseases Network of Piedmont and Aosta Valley) at HUB Giovanni Bosco Hospital in Turin. She is also engaged in university teaching and knowledge promotion in this specialized field. She is a member of CD ITALF.



### Dr Sandrine Mestre Godin (France)

Vascular physician and head of the lymphology care unit at CHU Montpellier (Reference Center for Rare Diseases -Primary Lymphoedemas). She is involved in developing innovative exploration techniques in lymphology and in teaching.



### Prof. Christine Moffatt (England)

Professor of clinical nursing at Nottingham University Hospital, a leading figure in lymphology. President of the International Lymphoedema Framework and co-founder of the Centre for Research and Implementation of Clinical Practice, dedicated to research on lymphoedema, wound management, and leg ulcers.

# Key Members of the 2024 Edition:



### Meadbh Mc Sneesey (Irland)

Advanced lymphoedema therapist, director of The Lymph Clinic, renowned for expertise in lymphoedema and other lymphatic disorders. Specializes in manual lymphatic drainage and decongestive lymphatic therapy.



### Prof. Jean-Paul Belgrado (Belgium)

Professor in physiotherapy and rehabilitation, specialized in lympho-venous edema treatment. He teaches at the Free University of Brussels and leads a lymphatic physiology laboratory, participating in and facilitating numerous educational activities worldwide.



### Dr Eulalia Baselga Torres (Spain)

Pediatric dermatologist specialized in hemangiomas and vascular lesions. Head of the Dermatology Service at Sant Joan de Déu Hospital in Barcelona, dedicating her career to research, teaching, and improving pediatric dermatological care.



### Dr Isabel Forner Cordero (Spain)

Specialist in Physical Medicine and Rehabilitation. For over 20 years, she has practiced at the Lymphology Unit of La Fe University Hospital in Valencia, Spain, focusing mainly on lymphoedema treatment. Alongside clinical practice, she plays an active role in research and education.

## Key International Speakers:



Prof. Stanley Rockson (USA)

Physician specializing in lymphoedema research and treatment. He is a professor of medicine at Stanford University and directs the Stanford Center for Lymphatic and Venous Disorders, where he conducts advanced research and trains future lymphology specialists.



#### Prof. Andrzej Szuba (Poland)

Internist specializing in lymphology and researcher at the University of Wrocław in Poland. Recognized for significant contributions to research and management of lymphatic diseases.



### Manuela Laurenço Marques (Portugal)

Engaged patient advocate for lymphatic disorders. Diagnosed with primary lymphoedema, she founded the andLINFA association in 2015 to support lymphoedema and lipedema patients. As president of andLINFA and a European Patient Advocacy Group (ePAG) member within VASCERN, she works to enhance patient care and support in Europe.



Betty Westbrook & Brittany Williams (USA)

Betty Westbrook, certified lymphoedema therapist in Texas, founder of "Camp Watchme," the American counterpart to international camps. Brittany Williams, founder of Brylan's Feat Foundation, dedicated to pediatric lymphoedema, committed to supporting children with this rare disease.

# Partners & Organizations:

Alongside these founding members, international partners and organizations work together to ensure an enriching experience for all participants.















CMID











ORGANIZATIONS

- Centre de Référence Maladies Rares Lymphœdèmes Primaires (CRMR) - Francia
- Partenariat Français du Lymphœdème (PFL) – Francia
- Association Vivre Mieux le Lymphoedème (AVML) – Francia
- Centro Di coordinamento delle Malattie rare del Pimonte e della Valle d'Aosta (CMID) - Italia
- Lymphido ODV Associazione di pazienti iltalia
- Italian Lymphoedema Framework (ITALF)
- International Lymphoedema Framework (ILF) – Regno Unito
- Lymphoedema Education & Research Network (LE&RN) – Stati Uniti
- VascERN Europa
- National Lymphoedema Framework Ireland (NLFI) -Irlanda

# logistics

# Dates & timings

Join us from **Wednesday, July 3rd to** Sunday, July 7th, 2024.

You can arrive **from 3 PM** on July 3rd and depart by **10 AM** on July 7th.

### Camp location

A five-star camping nestled in the heart of Ardèche.

Exact address:

1, route d'Alès-D111 Sampzon, 07120 Ruoms, France

### Transport

Need assistance getting to the camp? Contact us to explore available transportation options.

We recommend using a car if possible, as public transport or train access in the region is limited.





### Parking

Each mobile home has a dedicated parking space.

Additional parking is available on-site for extra vehicles.

For electric vehicles, charging stations are also available on-site.

### Accommodation & meals

You'll stay in air-conditioned mobile homes accommodating 2 to 6 people. Dinners are included for all participants and prepared by a caterer, offering vegetarian or pork-free options.

For other specific diets, please make necessary arrangements (<u>breakfast and</u> <u>lunch are not provided; please plan</u> <u>accordingly</u>).

Each mobile home is equipped with a kitchen. If you need provisions for breakfast and lunch, don't worry; the camping site has a restaurant, grocery store, and nearby shops.

#### IMPORTANT

For diets other than vegetarian or pork-free, please make your own arrangements.

Breakfast and lunch are not provided; please plan accordingly.

# **Upon Arrival**

### Welcome

Upon arrival, our team will greet you at the entrance. You'll receive all necessary information and your welcome kit!

If you opted for towel or sheet set services, please note that payment for these services will be settled with the camping site during your stay before departure.

### Accommodation assignment

Once checked-in, it's time to discover your mobile home. We'll accompany you to your accommodation.

### Welcome reception

Once settled, join us for a friendly welcome reception **from 4:30 PM** to 6 PM.

It's the perfect opportunity to meet, exchange, and immerse yourself in the camp atmosphere!

### 

# Upon departure

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## Key Return & Departure

Before saying goodbye, please follow these instructions:

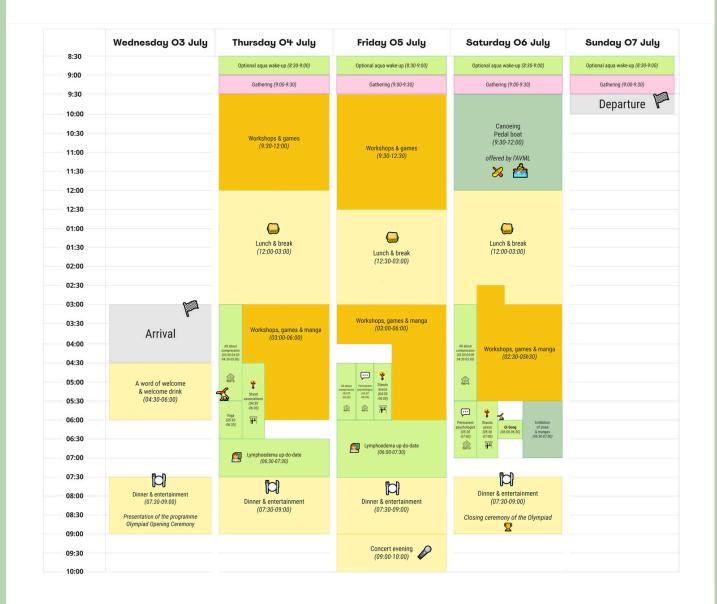
- Empty the refrigerator
- Wash your dishes and ensure nothing is left in the sink
- Sweep the mobile home
- Turn off the air conditioning, lights, and any other electrical appliances
- Take out the trash to the waste disposal area in the parking lot (please remember to separate your waste!)
- Leave sheets or towels outside the front door on the terrace, if you used these services
- Open all windows and leave the door slightly open
- Return the keys to the camping site reception or deposit them in the yellow mailbox if departing before 9 AM.

#### REMINDER

If you need to leave before the end of the camp, please inform us in advance.

Ensure to settle any sheet or towel services during your stay if you opted for these services.

# nrogram



# program

Discover an overview of the 2024 camp program.

Designed based on your feedback, it includes workshops for children with lymphedema, their siblings, and parents, along with shared moments. Some activities are optional, others recommended. You are free to choose your activities!

### Workshops

- Self-drainage & self-bandaging: Learn lymphatic drainage techniques and how to apply bandages with the help of physiotherapists. *Bandages will be provided, but please bring your usual materials (bandages, sleeves, stockings, etc.).*
- Support groups: Join discussion groups with a psychologist and other facilitators to share and exchange experiences among parents, children with primary lymphoedema, and siblings.
- Skin care & infection prevention: Discover expert advice and best practices to protect your skin without limiting your favorite activities!
- Orthosis fitting tutorials: Master tips for quickly donning compression garments with the help of experienced patients.
- Manga: For children and teens, create your own manga character in workshops led by a professional artist. Let your imagination run wild!

# program

### Drop-in sessions:

- Association information booths: Meet volunteer patients from the "Living Better with Lymphoedema" Association (France) and Lymphido (Italy) for information, resources, and support related to lymphedema.
- Psychological support: A psychologist is available for individual or family sessions in a dedicated mobile home.
- Compression: A lymphology professor will explain compression methods in an engaging way—a chance to learn while having fun!
- Lymphoedema Up-to-date: At the end of the day, attend presentations on lymphedema, covering clinical aspects, current research, and international initiatives.

### Activities

- Olympics: Children and teens can participate in Olympic-themed games tailored for all abilities—a perfect opportunity to make new friends and break the ice!
- Canoeing, kayaking, and pedal boating: Spend a family morning on the Ardèche gorges. Pedal boats for younger ones and kayaking for older participants, courtesy of the AVML association.
- Qi-gong: Join three sessions of this ancient Chinese practice beneficial for the lymphatic system, led by a volunteer.

# preparations

# What to bring

To fully enjoy your stay, remember to pack comfortable clothing suitable for the weather, toiletries, swimwear, and comfortable outdoor footwear.

To ensure your experience at the camp is as enjoyable as possible, here's a comprehensive list of recommended items to pack in your luggage.

Make sure to bring along your usual devices, including any older ones.

- Swimwear (note: swim shorts are prohibited in the campsite pool)
- Sunscreen
- Hat or cap
- Sunglasses
- Rainwear
- Small backpack
- Sports shoes
- Water shoes / closed-toe shoes for water activities
- Flashlight or headlamp
- Mosquito repellent
- Sweater (evenings can be cool)
- Musical instrument (if you or your child plays one, feel free to bring it to camp!)
- Yoga mat or exercise mat (if available and portable)
- Bath towels (if not provided)
- Bed sheets (if not provided)
- Typically used lymphoedema management materials (bandages, stockings, sleeves...)

# On-site

Here's a quick overview of the facilities and services available onsite:

### Activities & Leisure

- Heated pool with water slide (open from 9am to 8pm)
- Beach on the Ardèche River (river access open from 7am to 11pm)
- Game rooms, petanque courts, and ping-pong
- On-site dining with a bar (open from 9am to 11pm) and snacks (from 12pm to 10pm)
- Playground

### Services

- Reception (open from 9am to 8pm)
- Grocery store (open from 8am to 8pm)
- Laundromat
- Information point and library
- Free WiFi access throughout the campsite
- Adapted sanitary facilities
- Electric vehicle charging stations (charging on mobile homes prohibited)
- Parking and camper service area
- Bicycle and go-kart rental
- BBQ / griddle (available with the mobile home)

# man



# equipment

### In your accommodation

### • Equipped kitchen

- Cooktop
- Refrigerator/freezer
- Microwave
- Coffee maker
- Kitchen utensils
- Barbecue
- Double bed (dimensions: 1.6 x 2 meters)
- Single beds (dimensions: 0.8 x 1.9 meters)
- Duvets
- Sink
- Toilet
- Shower cabin
- Flat screen TV / television (in some accommodations)
- Dishwasher (only in 6-person accommodations)
- Combined oven/microwave (only in 6-person accommodations)
- Whistling kettle (only in 6-person accommodations)

### BED DIMENSIONS

Double beds: **1.6 x 2 m** Single beds: **0.8 x 1.9 m** 

# Nearhy

### Shops

- Super U Drive, 5 minutes by car.
- Lidl, 5 minutes by car.
- Intermarché Super Vallon Pont d'Arc, 11 minutes by car

### Bakery

• Boulangerie Constant Ruoms, 10 minutes by car.

### Gas station

- Total Energies Contact Grospierres, 4 minutes by car.
- Intermarché Station-Service Vallon-Pont-D'arc, 12 minutes by car.

### Tobacconist

• Tabac Mag Press, 8 minutes by car.

# ATM

Crédit Agricole Vallon Pont d'Arc, 11 minutes by car



### Pets Allowed

Can I bring my dog with me?

Of course! The campsite welcomes pets. They are allowed as long as they are kept on a leash and vaccinated (maximum 1 per accommodation).

If this applies to you, please inform us as soon as possible.

# Smoking Policy

Is smoking allowed at the campsite?

Yes, you can smoke in designated areas of the campsite. However, smoking is prohibited inside the accommodations or other facilities. For ecological reasons, please use the designated areas to dispose of your cigarettes. We appreciate your understanding.

# **Baby Items**

I'm coming with my baby, what items are available in the accommodation?

The campsite offers the rental of baby cots, baby baths, and high chairs.

If this applies to you, please inform us as soon as possible.

### WiFi Access

Is WiFi available?

Yes, free WiFi access is available. To connect: search for and select the network named "RCN Hotspot" and simply accept the terms and conditions.

# Additional Informations

## COVID-19

With the resurgence of COVID, we ask you to take precautions before coming. It is advisable to wear a mask if you have any doubts or symptoms. Please also follow the current health measures.

#### HOSPITAL ADDRESS

Hôpital Saint Eloi (CHU de Montpellier) Service de médecine vasculaire 80, avenue Augustin Fliche 34090 Montpellier, France

### Montpellier Accommodations

Below is a list of accommodations near the Hôpital Saint Eloi (CHU de Montpellier) for families coming for consultations before the camp.

- Hôtel Les Troènes
  - Website: <u>Hôtel Les Troènes</u>
  - Location: Lien Google Maps
- Hôtel Lapeyronie
  - Website: <u>Hôtel Lapeyronie</u>
  - Location: Lien Google Maps
- Maison d'Accueil Hospitalière La Pasquière
  - Website: <u>La Pasquière, Maison</u> <u>d'Accueil Hospitalière</u>
  - Location: Lien Google Maps
  - *Note*: Toilets are located in the corridor.

# Additional Informations

## Image Rights

Please send the documents related to image rights (acceptance or refusal) for each family member via email. Complete and sign them, then send by email to the following addresses:

- domitille.ferron@chu-montpellier.fr
- morgane.denis@chumontpellier.fr

### Research during the Camp

During the camp, families are invited to participate in research projects aimed at enhancing the understanding and treatment of primary lymphoedema in children.

This opportunity allows families, if they wish, to contribute directly to the advancement of medical knowledge and the improvement of care. These projects will be presented at the beginning of the camp.

### Communication during the Camp

During the camp, we will use a WhatsApp group to announce daily activities and share schedules.

Each morning (from 9:00 to 9:30), gatherings will be organized to announce the day's events and detail the program.

Additionally, a central bulletin board will be available at all times to check the program, essential information, and important announcements.

### Contacts

### **Domitille Ferron**

(Camp Coordinator)

- Email: <u>domitille.ferron@chu-</u> <u>montpellier.fr</u>
- Phone: +33 6 30 38 72 27

### **Morgane Denis**

(Camp Coordinator)

- Email: <u>morgane.denis@chu-</u> <u>montpellier.fr</u>
- Phone: +33 6 31 51 42 76

### **Maurice Delwel**

(Campsite Manager)

- Email: <u>m.delwel@rcn.fr</u>
- Phone: + 33 6 70 94 55 17