

1ST INTERNATIONAL AL AMYLOIDOSIS MEETING

FOR PATIENTS AND DOCTORS



July 5-6, 2024
BRUSSELS



ALamyloidosismeeting.com

PROGRAM

ORGANIZED BY:



WITH THE COLLABORATION OF:



**1ST INTERNATIONAL
AL AMYLOIDOSIS
MEETING**

FOR PATIENTS AND DOCTORS

July 5-6, 2024
BRUSSELS



JOIN US

IN BRUSSELS!

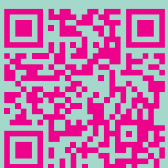
The Amyloidosis Alliance is pleased to welcome you to the first International AL Amyloidosis Meeting, which will be held in Brussels on July 5-6, 2024.

This two-day program will be an extraordinary opportunity to gain insights into all aspects of AL amyloidosis, with a special focus on managing complications linked to organ involvement. It will also provide occasions for patients and medical doctors to learn from each other's experiences.

On the first day, there will be sessions dedicated to patients, and separate sessions for doctors. The second day will feature joint sessions for both groups.

We hope to meet you in Brussels and wish you an inspiring congress!

Agnès FARRUGIA, Frank BRIDOUX and Nathalie MEULEMAN
On behalf of the organizing committee



REGISTRATION AND INFORMATION:
ALamyloidosismeeting.com



ORGANIZING COMMITTEE

- **Prof. Nathalie MEULEMAN**
Institut Jules Bordet (HUB),
Brussels, Belgium
- **Prof. Frank BRIDOUX**
Centre de référence
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- **Jean-Christophe FIDALGO**
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- **Agnès FARRUGIA**
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- **Prof. Arnaud JACCARD**
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- **Prof. Efstathios KASTRITIS**
National and Kapodistrian
University of Athens, Greece
- **Prof. Olivier LAIREZ**
Institut des Maladies
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Cardiovasculaires,
Toulouse, France
- **Barbara MAZZOLINI**
Association Française
contre l’Amylose, France
- **Prof. Monique MINNEMA**
Academic Medical Center,
Utrecht, The Netherlands
- **Drs Ben WOLTERING**
Amyloidosis Alliance,
The Netherlands

SCIENTIFIC COMMITTEE

- **Prof. Antoine BONDUE**
Hôpital Universitaire
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- **Prof. Frank BRIDOUX**
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- **Prof. Thibaud DAMY**
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- **Agnès FARRUGIA**
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- **Prof. Ute HEGENBART**
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- **Prof. Arnaud JACCARD**
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Toulouse, France
- **Dr Nelson LEUNG**
Mayo Clinic, Rochester, USA
- **Barbara MAZZOLINI**
Association Française contre
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- **Prof. Nathalie MEULEMAN**
Institut Jules Bordet (HUB),
Brussels, Belgium
- **Prof. Monique MINNEMA**
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- **Prof. Giovanni PALLADINI**
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Treatment Center, Pavia, Italy
- **Dr Virginie PASCAL**
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- **Prof. Stefan SCHÖNLAND**
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für Innere Medizin,
Heidelberg, Germany
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CHU de Limoges, France
- **Prof. Ben SPRANGERS**
Ziekenhuis Oost-Limburg,
Leuven, Belgium
- **Prof. Ashutosh
WECHALEKAR**
Royal Free London Foundation
Trust, Great Britain
- **Drs Ben WOLTERING**
Amyloidosis Alliance,
The Netherlands



FRIDAY, JULY 5

**DOCTORS
CHANNEL**

08:00 - 08:30 am

REGISTRATION

08:30 - 09:00 am

INTRODUCTION

09:00 - 10:00 am

SESSION 1A

Latest medical advances in pathophysiology

Stefano Ricagno (Milano, Italy), Arnaud Jaccard (Limoges, France)

Chairmen:

09:00

Recent insights into the structure and formation of AL amyloid fibrils
Marcus Fändrich (Ulm, Germany)

09:15

Recent insights from in vivo models into AL amyloid fibrils accumulation and toxicity for organs
Christophe SIRAC (Limoges, France)

09:30

How do fibrils disappear? **Remoted presentation**
Julian Gillmore (London, Great Britain)

09:45

Discussion

10:00 - 11:20 am

SESSION 2A

Supportive care of treatments of involved organs - Part 1

Chairmen:

Thibaud Damy (Créteil, France), Helen Lachmann (London, GB)

10:00

Kidney
Lluis Quintana (Barcelona, Spain)

10:20

Kidney transplantation
Nelson Leung (Rochester, USA)

10.40

Cardiac
Michelle Michels (Rotterdam, The Netherlands)

11.00

Round table

11:20 - 11:50 am

Coffee break | Visit exhibit

11:50 am - 01:00 pm

SESSION 2A

Supportive care of treatments of involved organs - Part 2

Chairmen:

*Nelson Leung (Rochester, USA),
Michelle Michels (Rotterdam, The Netherlands)*

11:50

Peripheral nervous system
Michela Bisciglia (Bruxelles, Belgique)

12:10

Others: GI, nutrition, hypotension, fatigue, muscle loss, sexual dysfunction
Ornella Rizzo (Brussels, Belgium)

12.30

Round table



FRIDAY, JULY 5

**DOCTORS
CHANNEL**

.../...

01:00 - 02:30 pm Lunch time

02:30 - 03:15 pm

SYMPOSIUM

A multidisciplinary approach to managing systemic light chain (AL) Amyloidosis



Stefan Schönland (Heidelberg, Germany), Adam Ioannou (London)

03:15 - 04:30 pm

SESSION 3A

How to assess the response to treatments?

Chairmen: *Nathalie Meuleman (Brussels, Belgium),
Monique Minnema (Utrecht, The Netherlands)*

- 03:15 **Biology of the clone**
Stefan Schönland (Heidelberg, Germany)
 - 03:35 **Utility of minimal residual disease assessment in AL Amyloidosis**
Ashutosh Wechalekar (London, Great Britain)
 - 03:55 **Light chain instability in AL amyloidosis** Remoted presentation
Jeffery Kelly (La Jolia, USA)
 - 04.15 Discussion
-

04:30 - 05:00 pm Coffee break | Visit exhibit

05:00 - 06:30 pm

SESSION 4A

Complex clinical cases

Chairmen: *Frank Bridoux (Poitiers, France), Stefan Schönland (Heidelberg, Germany)*

- Diagnostic
- Difficult treatment
- Long term remission

06:30 pm **END OF THE FIRST DAY**

08:15 pm **DINNER**

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PATIENTS

ASSOCIATIONS

CHANNEL

FRIDAY, JULY 5

08:00 - 08:30 am

REGISTRATION

08:30 - 09:00 am

INTRODUCTION

Amyloidosis Alliance introduction and actions

Jean-Christophe Fidalgo, president

09:00 - 10:45 am

SESSION 1B

Diagnosis improvement and 2024 critical point

Chairmen:

Roland Drewinski (Germany), Olivier Lairez (Toulouse, France)

09.00

Diagnosis: patients journey testimonies

09.30

How to reduce time to diagnosis in 2024?

Nathalie Meuleman (Brussels, Belgium)

09:50

How to improve the accurate diagnosis in 2024?

Christoph Röcken (Kiel, Germany)

10:10

Multidisciplinary approach for improving the diagnosis?

Olivier Lairez (Toulouse, France)

10:30

Discussion

10:45 - 11:15 am

Coffee break

11:15 am - 01:00 pm

SESSION 2B

Medical care and symptoms treatment

Chairmen:

Thibaud Damy (Créteil, France), Helen Lachmann (London, GB)

11:15

Kidney

Lluis Quintana (Barcelona, Spain)

11.30

Others (malnutrition, macroglossia, dysgeusia)

Ornella Rizzo (Brussels, Belgium)

11:45

Dialysis

Anne-Lorraine Clause (Brussels, Belgium)

12.00

Cardiac

Christian Knackstedt (Maastricht, The Netherlands)

12.15

Peripheral nervous system

Michela Bisciglia (Bruxelles, Belgique)

12.30

Discussion



PATIENTS ASSOCIATIONS CHANNEL

FRIDAY, JULY 5

.../...

01:00 - 02:30 pm Lunch time

02:30 - 04:00 pm

SESSION 3B

Importance of self-care: physical, mental and emotional wellbeing

Chairmen: Ric-Paul Hammink (Amyloidosis Alliance, The Netherlands),
Barbara Mazzolini (Association Française contre l'Amylose, France)

- 03:30 Complementary treatments: the French experience
Julie Pompougnac (Créteil, France)
- 02:45 Kinesiology / Music therapy
Audrey Norris, Barbara Mazzolini (Association Française contre l'Amylose, France)
- 03:00 Dietetic and environment during and after the treatment
Marianna Arvanitaki (Brussels, Belgium)
- 03:15 Physical training for amyloidosis patients during the treatment
Benjamin Depoorter (Brussels, Belgium)
- 03:30 Role of patient's organisation and care givers
David Gregory (The Ukpata, Great Britain)
- 03:45 Discussion

04:00 - 04:30 pm Coffee break

04:30 - 05:15 pm

SESSION 4B

Return to normal life after treatment

Chairmen: Agnès Farrugia (Association Française contre l'Amylose),
Guy Lippens (Amybel, Belgium)

- 04:30 Vaccines and prevention
Ornella Rizzo (Brussels, Belgium)
 - 04:45 Muscular rehabilitation and sport
Julien Mathias (Association Française contre l'Amylose)
 - 05:00 Discussion
-

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PATIENTS

ASSOCIATIONS

CHANNEL

FRIDAY, JULY 5

.../...

05:15 - 06:15 pm

SESSION 5B

Return to work

Chairmen: Barbara Mazzolini (Association Française contre l'Amylose, France), Ben Woltering (Amyloidosis Alliance, The Netherlands)

05:15 Testimonies: return to work share experience

05:30 Round table

Return to the same work? How to adapt work and manage fatigue?

With the participation of: Susan Booth (Australian Amyloidosis Network, Australia), Teresa Deutsch (Amyloidosis Support Groups, USA), Julien Mathias (Association Française contre l'Amylose), Julie Pompougnac (Créteil, France)

06:15 pm

END OF THE FIRST DAY

08:15 pm

DINNER



SATURDAY, JULY 6

**DOCTORS
& PATIENTS
CHANNEL**

09:00 - 09:15 am

REGISTRATION

09:15 - 11:00 am

SESSION 6
2024 ISA news

Chairmen: **Bouke Hazenberg (Groningen, The Netherlands),
Stefan Schönland (Heidelberg, Germany),
Ben Woltering (Amyloidosis Alliance, The Netherlands)**

- 09:15 Introduction: standards of care in 2024 and current challenges
Arnaud Jaccard (Limoges, France)
- 09:35 Discussion
- 09:45 Latest developments in treatment
Efstathios Kastiris (Athens, Greece)
- 10:05 Discussion
- 10:15 New diagnostic tools and technologies
Hans Nienhuis (Groningen, The Netherlands)
- 10:35 Discussion

11:00 - 11:30 am

Coffee break

11:30 am - 12:45 pm

SESSION 7
Treatment management

**Johnson
& Johnson**

Chairmen: **Nathalie Meuleman (Brussels, Belgium),
Barbara Mazzolini (Association Française contre l'Amylose)**

- 11:30 The goals of treatment
Paolo Milani (Pavia, Italy)
- 11.50 Potential side effects and how to manage them
Michel Delforge (Leuven, Belgium)
- 12.10 Why and when to stop the treatment
Monique Minnema (Utrecht, The Netherlands)
- 12.30 Discussion



**DOCTORS
& PATIENTS
CHANNEL**

SATURDAY, JULY 6

.../...

01:00 - 02:15 pm Lunch time | Visit exhibit

02:15 - 04:00 pm

SESSION 8

Treatments in 2024 and beyond

Chairmen: *Frank Bridoux (Poitiers, France),
Ric-Paul Hammink (Amyloidosis Alliance, The Netherlands)*

- 02:15 **Initial patient-tailored treatment strategy**
Marie-Christiane Vekemans (Brussels, Belgium)
 - 02:35 **Relapse treatment strategy**
Ashutosh Wechalekar (London, Great Britain)
 - 02:55 **Ongoing clinical trials**
Ute Hegenbart (Heidelberg, Germany)
 - 03:15 **Position of organ transplantations in 2024**
Nelson Leung (Rochester, USA)
 - 03:35 **Discussion**
-

04:00 - 04:15 pm

CONCLUSION

04:15 pm **END OF THE MEETING**

GENERAL INFORMATION



VENUE:

nhow Brussels Bloom
Rue Royale 250
B - 1210 Brussels
+32 2 220 66 11
www.nhow-hotels.com

ACCESS:

From the Brussels airport:

- Taxi: 30/40 minutes trip
- Public transport: train to Brussels North Station (15 minutes), then 10 minutes walk or 5 minutes taxi ride to the hotel

From train:

- Brussels North station (850 meters away from the hotel)
- From Brussels-Midi station: 15/20 minutes taxi ride or 25 minutes by metro (line 2)

Public transport:

- Tram 92 and 93: stop Botanique (150 meters away from the hotel)
 - Metro line 2 and 6: stop Botanique (150 meters away from the hotel)
- www.stib-mivb.be

LANGUAGE:

Official language: English
Translation available (for patients only, in person): English/French

REGISTRATION FEES

	BEFORE 31/05/2024	FROM 01/06/2024
• Doctors	€330	€380
• Paramedical professions	€120	€170
• Fellows / Students *	€100	€150
• Patients / Association's representatives	€30	€50
• Industry	€850	€950
• Streaming (only online)	€125	€175
• Dinner	€70	€70

*On presentation of proof

The registration fees include: attendance to all scientific sessions, congress kit, lunches, coffee breaks.

CANCELLATION POLICY:

Until 10/06/2024: 100% refund with administrative fees of 20 Euros deducted
From 11/06/2024: no refund

ACCOMMODATION HOTEL NHOW:

www.nh-hotels.com
Contact: Alec MIKAILIAN
a.mikailian@nhow-hotels.com | +3222206906

CONGRESS DINNER:

July 5, from 8.00 pm

Come and share a moment of conviviality in a warm place in the heart of Brussels. An evening that will highlight the specialties of Belgian gastronomy!

La Brasserie des Alexiens

Rue des Alexiens 63, 1000 Bruxelles
<https://brasserie-des-alexien.be/>
1,9 km from the hotel nhow (30 minutes walk)
Tram 92 or 93: stop Petit Sablon (20 minutes)

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**COMM
Santé**