



SSIEM 2024

Annual Symposium

03-06 September

Porto, Portugal

Exploring New
Horizons

Final Report

SSIEM 2024 | 03-06 September
Annual Symposium | Porto, Portugal
Exploring New Horizons

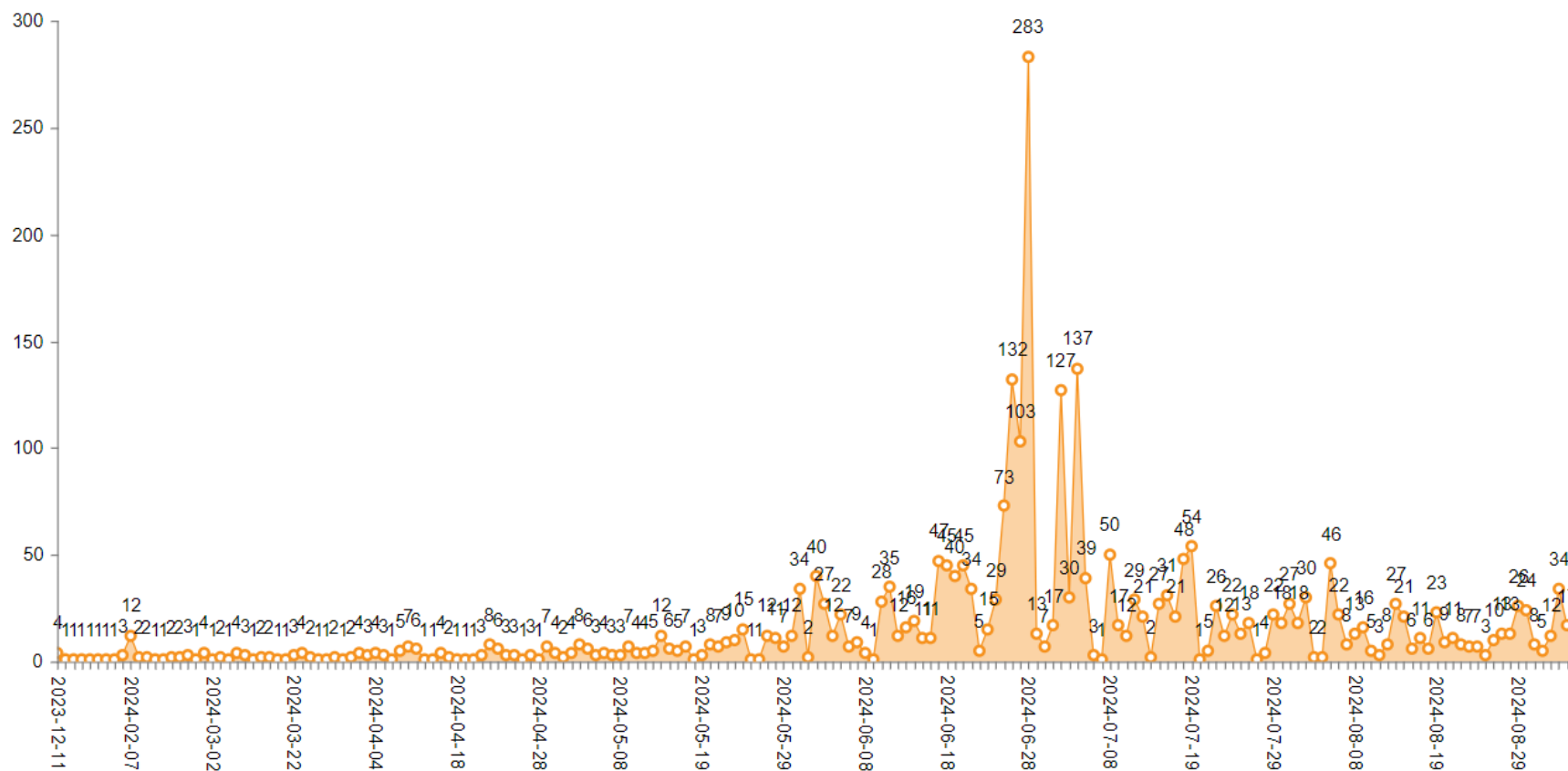
REGISTRATIONS





The Symposium had a total of **2817 registrations**.

REGISTRATION EVOLUTION



Category	Quantity
Exhibitor ´s registration	269
Guests for the 60th Aniversary	8
Patient Advocacy Group	13
Speakers	35
Press	6
Scholarships	6
Council Members	10
Honorary Officers	3
Industry Members	63
Industry Members (complimentary)	6
Industry Non Members	392
Industry Non Members(complimentary)	100

Category	Quantity
JIMD Editors	7
Local Organiser Committee	6
Participant Member	498
Participant Non Member	1081
Sponsorship	268
Staff/CLO	3
Travel Scholarships	32
Ukraine Participants	11
TOTAL	2817



92 countries

Country	Quantity
Algeria	14
Argentina	32
Armenia	2
Australia	33
Austria	37
Azerbaijan	2
Bahrain	2
Belgium	60
Bosnia and Herzegovina	1
Brazil	36
Bulgaria	14

Country	Quantity
Canada	26
Chile	3
China	3
Choose from the list	49
Colombia	27
Costa Rica	2
Croatia	13
Cyprus	6
Czech Republic	28
Denmark	22
Ecuador	1
Egypt	9

Country	Quantity
Estonia	7
Finland	24
France	76
Georgia	2
Germany	176
Greece	36
Guatemala	1
Hong Kong	8
Hungary	14
Iceland	4
India	11

Country	Quantity
Iran	8
Iraq	16
Ireland	9
Israel	33
Italy	209
Japan	54
Jordan	2
Kazakhstan	9
Korea, North	1
Korea, South	30
Kosovo	1
Kuwait	6



Country	Quantity
Latvia	4
Lebanon	4
Lithuania	7
Luxembourg	5
Malaysia	6
Mexico	10
Moldova	1
Montenegro	3
Morocco	18
Netherlands	129
New Zealand	5

Country	Quantity
Nigeria	1
Norway	19
Oman	2
Pakistan	2
Paraguay	2
Peru	1
Philippines	11
Poland	59
Portugal	199
Qatar	11
Romania	18
Russia	22

Country	Quantity
Saudi Arabia	27
Serbia	11
Singapore	5
Slovakia	12
Slovenia	9
South Africa	3
Spain	190
Sri Lanka	2
Sweden	58
Switzerland	73
Syria	1
Taiwan	25

Country	Quantity
Thailand	1
Tunisia	9
Turkey	103
Ukraine	13
United Arab Emirates	19
United Kingdom	249
United States of America	299
Uruguay	2
Uzbekistan	2
Vietnam	4
Thailand	1
Tunisia	9

TOP 7:

United States of America (299)
 United Kingdom (249)
 Italy (209)
 Portugal (199)

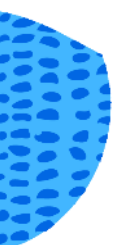
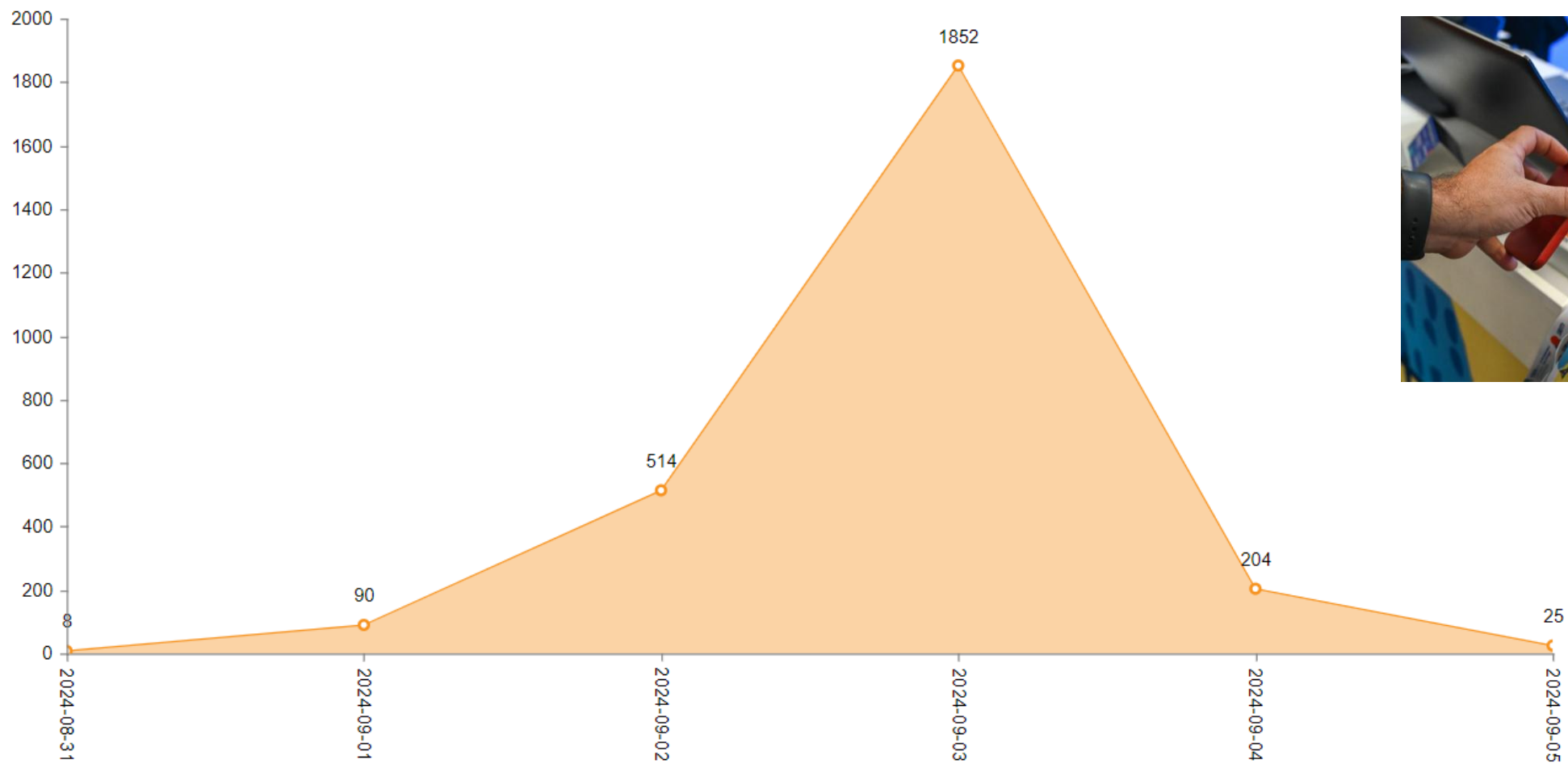
Spain (190)
 Germany (176)
 The Netherlands (129)



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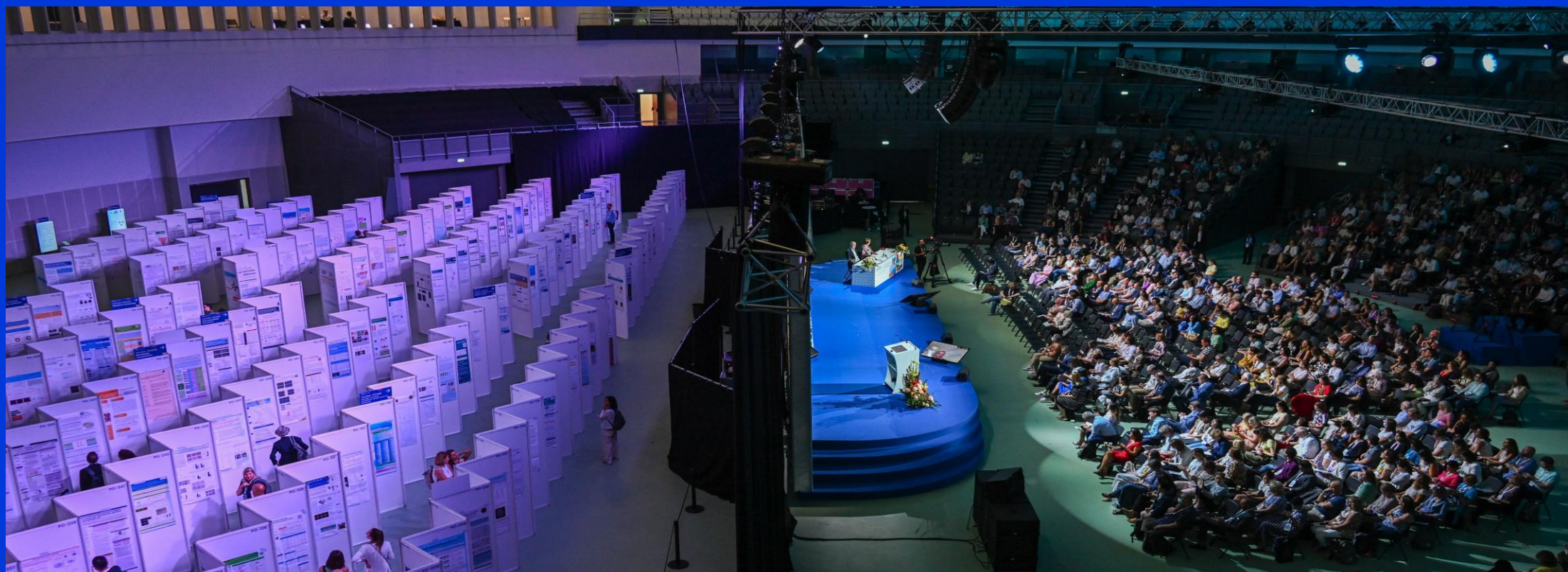
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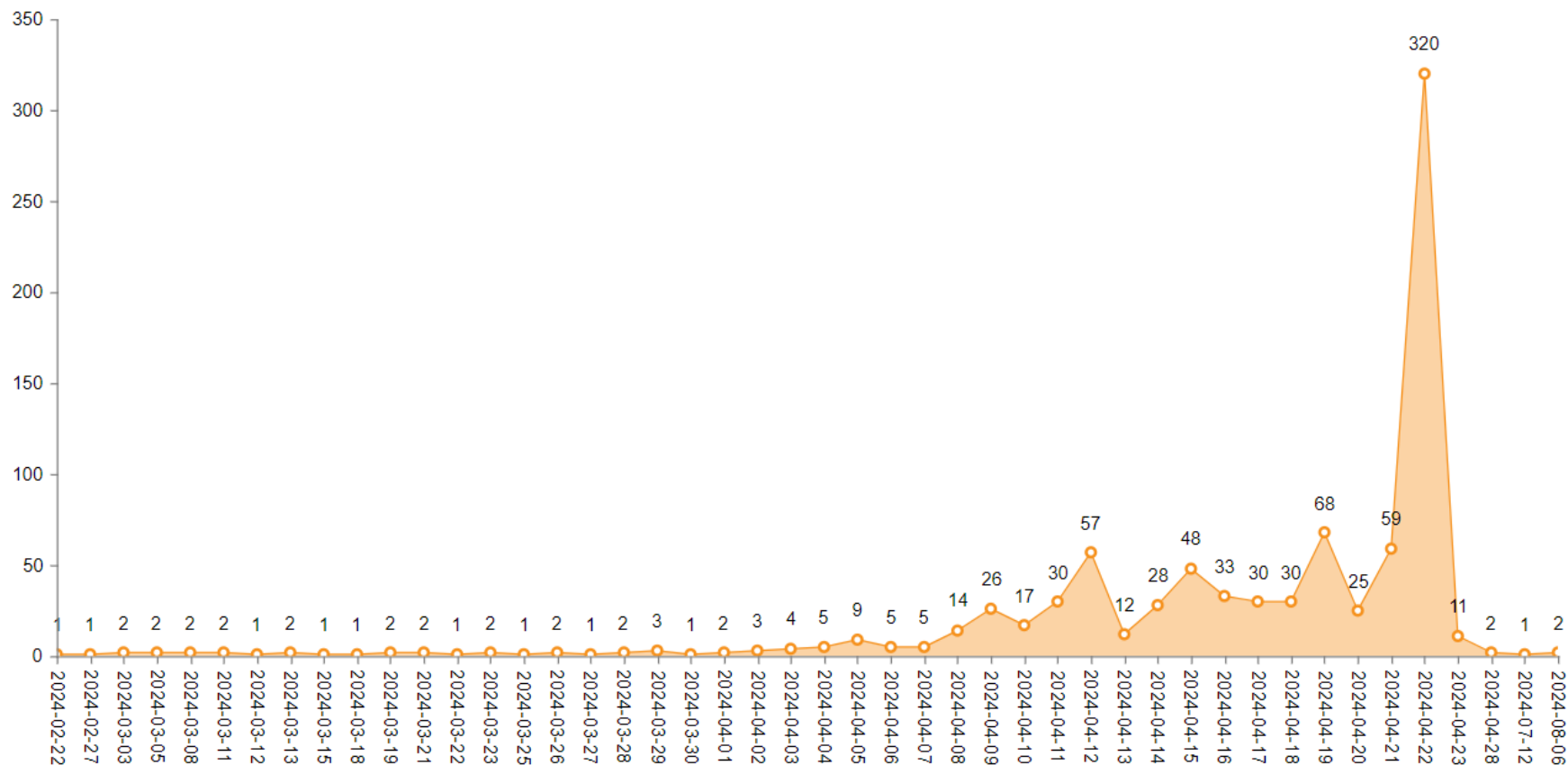
CHECK IN EVOLUTION



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ABSTRACTS



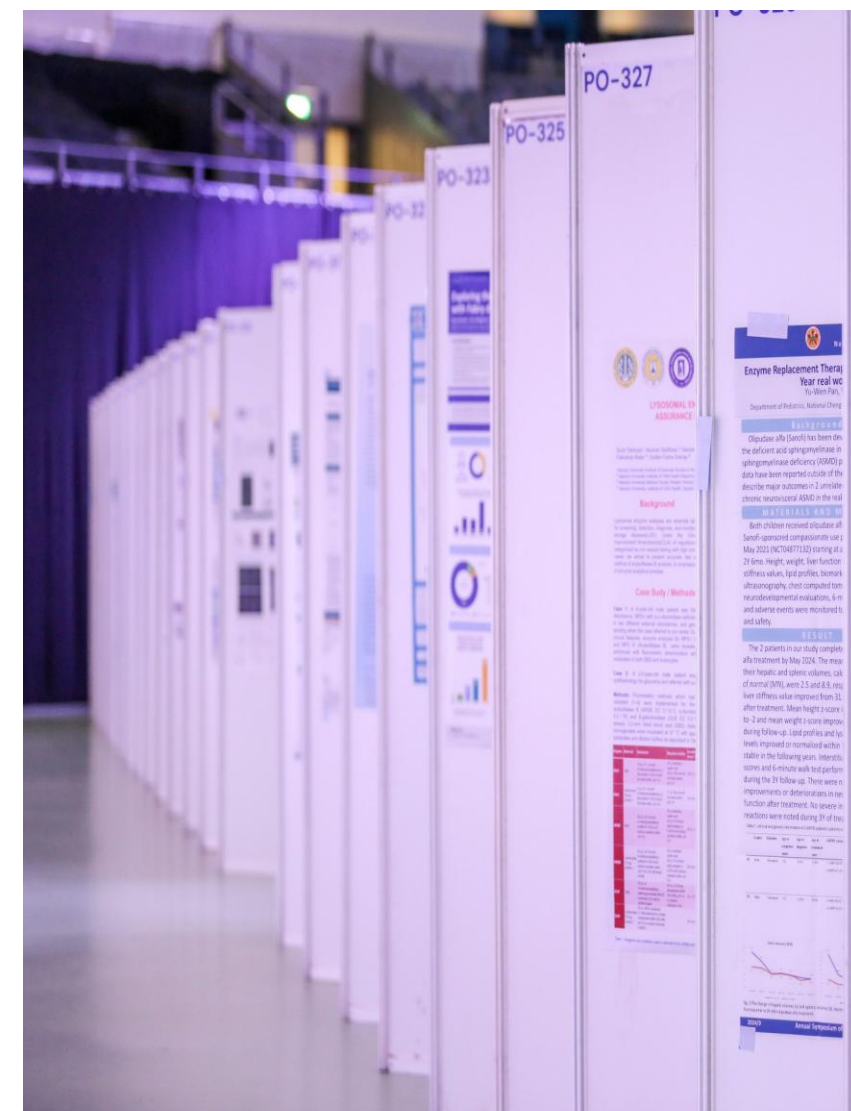


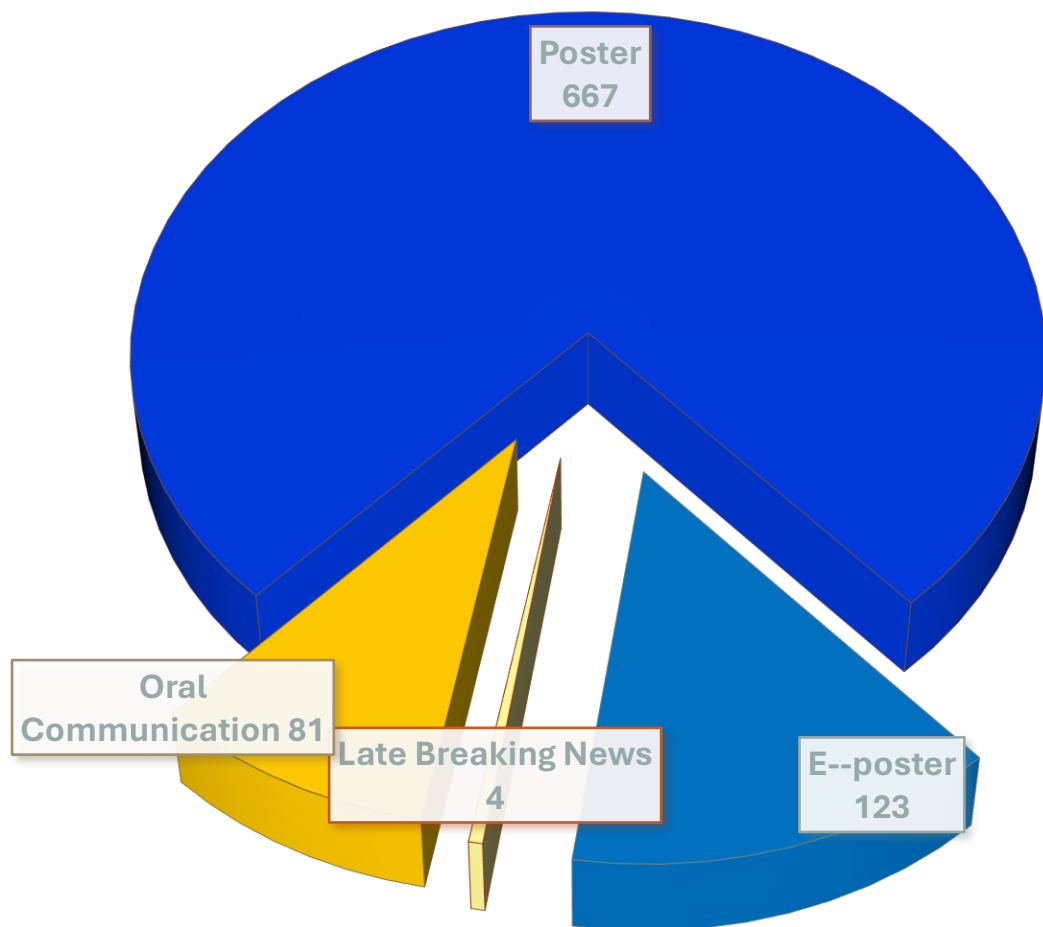
Of the **854 abstracts submitted**, 845 were approved reviewed by **145 reviewers**.



Theme	Submission
Amino acid disorders	41
Carbohydrate disorders	30
Clinical studies, patient reported outcome measures	41
Dietetics and nutrition	41
Disorders of fatty acid oxidation and ketone body metabolism	39
Disorders of purines, pyrimidines, nucleic acids and porphyrias	11
Disorders of vitamins, cofactors and trace elements	30
Glycosylation disorders/CDG, protein modification disorders	25
Innovative therapies such as RNA-based therapy, gene therapy and regenerative medicine	30

Theme	Submission
Lysosomal disorders	177
Metabolic myopathies	4
Mitochondrial disorders	85
Neurotransmitter and creatine related disorders	23
New Diseases	15
Newborn screening	41
Novel diagnostic/laboratory methods including omics	38
Nursing in metabolism	22
Organic acidurias	37
Peroxisomal, sterol, bile acid, lipid and lipoprotein metabolism	25
Phenylketonuria	46
Urea cycle disorders	53





New format – Selected HIGH RANKED POSTERS - 30

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ATTENDANCE PER ROOM





Session	Attendance
E-IMD Members Meeting	27
Recommendations on CGM use in GSD	26
HOD/E-IMD Joint Meeting	24
E-HOD Members Meetings	17
PM-MD MetabERN	11
NBS Collaboration Meeting MetabERN	33
NOMS SNW MetabERN	Private meeting
MetabERN Meeting	74
EHOD executive board meeting	5
SSIEM-DG Academy review: addressing dietetic challenges	103
AOA SNW MetabERN	25
LSD SNW MetabERN	28
C-FAO SNW MetabERN	15
CDG SNW MetabERN	3
PD SNW MetabERN	3

10 special group meetings; 7
 MetabERN meetings
 5 ERNDIM





Session	Attendance
SSIEM Adult Metabolic Group meeting	237
ERNDIM Workshop: DPT France	17
ERNDIM Workshop: DPT Czech Republic	12
ERNDIM Workshop: DPT Netherlands	18
ERNDIM Workshop: DPT Switzerland	16
Nutrition and Dietetic Session	35
JIMD Editorial Board meeting	
ERNDIM Workshop: DPT UK	
Recon4IMD	26
GALNET	32
ERNDIM Workshop	131

Session	Attendance
Adult Metabolic Group business meeting	40
Satellite Symposia: Sanofi	162
Satellite Symposia: Ultragenix	
Satellite Symposia: PTC	187
Satellite Symposia: Takeda	205
Opening Ceremony	1345
Opening lecture	1304
Plenary Session: Looking behind genes and proteins I	784
Plenary Session: Looking behind genes and proteins II	613





Session	Attendance
Satellite Symposia: Amicus Therapeutics	176
Satellite Symposia: Chiesi	121
Satellite Symposia: Immedica	140
Satellite Symposia: Iecure	97
Speed Mentoring	21
IOC Meeting	9
Parallel Session: Lysosomal Disorders: Mechanisms, biomarkers and treatments	550
Educational session: Neurometabolism: from symptoms to biochemistry and diagnosis	455
SSIEM Dietitian Group meeting	285
Patient Advocacy Groups session I	151
Patient Advocacy Groups session II	151
Coffee with the Editor	18
Plenary Session: Beyond energy metabolism	955

Session	Attendance
MGM editor meeting	9
SSIEM Advisory Council & Council Meeting	
SSIEM AGM	
Parallel Session: Mitochondrial Disorders	613
Parallel Session: Dietetics and nutrition	40
Parallel Session: Protein modification disorders, including CDG	198
Parallel Session: Novel diagnostic technologies	316
Plenary Session: Navigating new seas in IEM phenotyping	837
Satellite Symposia: Applied	64
Satellite Symposia: Biomarin	174
Satellite Symposia: Recordati	118





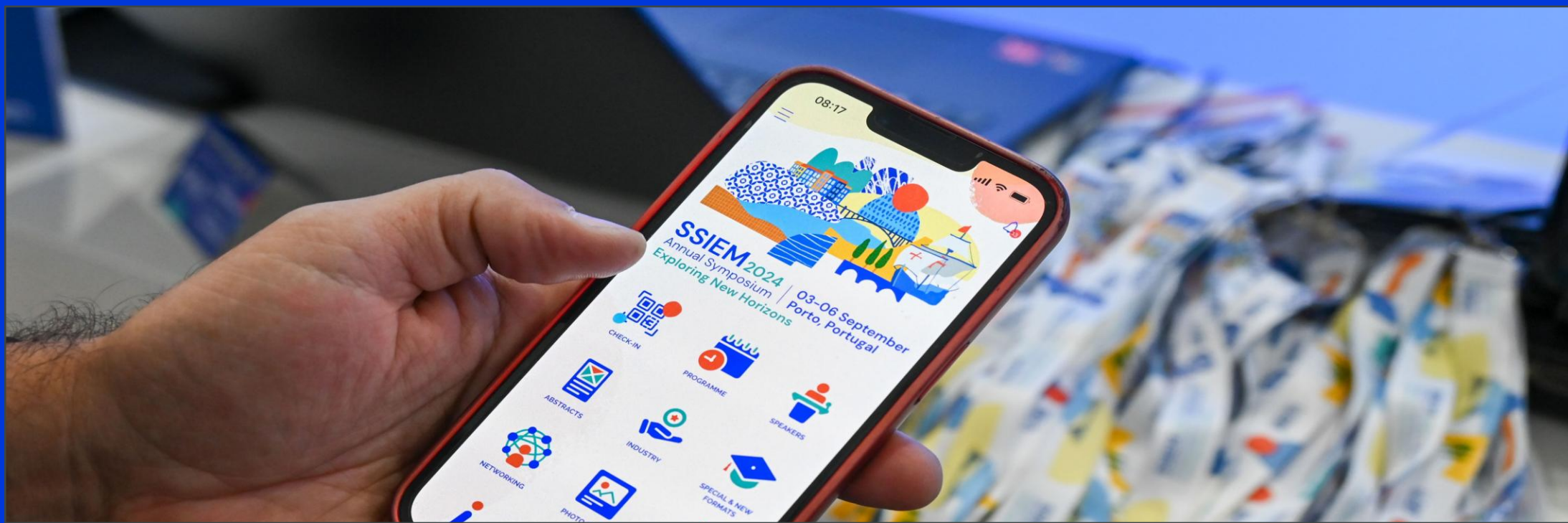
Session	Attendance
Satellite Symposia: Amicus	120
Satellite Symposia: Jnana	120
Satellite Symposia: Mirum	71
Speed Mentoring	21
Plenary Session: Modelling IEM	773
Parallel Session: Innovative Therapies	584
Parallel Session: Carbohydrate Disorders	200
Parallel Session: Amino acids	268
Parallel Session: Disorders of Vitamins and Cofactors	119
Parallel Session: Nursing in Metabolism	199
Satellite Symposia: Chiesi	241
Satellite Symposia: PTC	

Session	Attendance
Satellite Symposia: SANOFI	130
Satellite Symposia: Orchard	139
JIMD Communicating Editors meeting	22
Parallel Session: Clinical studies & outcomes	277
Parallel Session: Neurometabolic Disorders	165
Parallel Session: Protein intoxication disorder	178
Parallel Session: Fatty acid oxidation and related disorders	234



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COMMUNICATION & OTHER PLATAFORMS



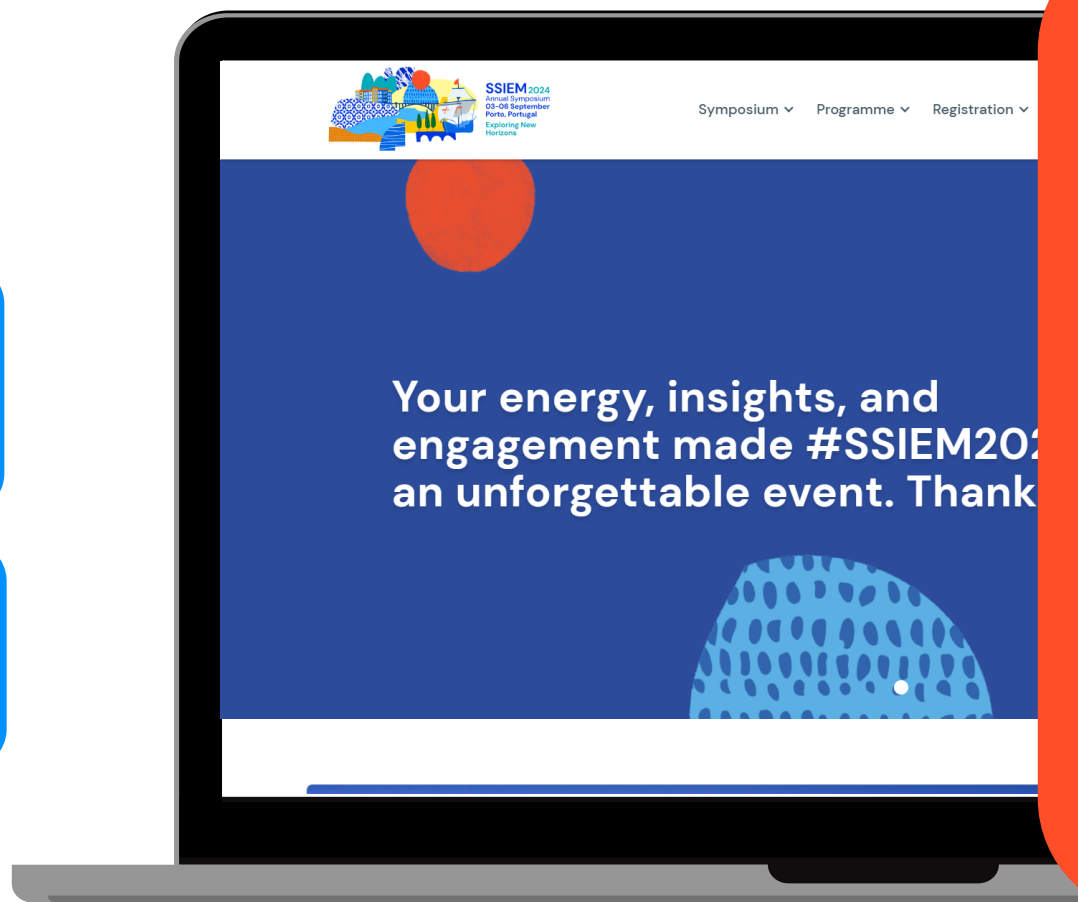
The website was launched
on **September 01, 2024**

47 124

Total of Users

198 483

Total of Views



Top 5 countries most visited:

	Users
USA	8 425
Portugal	5 843
United Kingdom	3 872
Spain	2 653
Italy	2 481

Top 5 most visited pages:

	Views
Homepage	66 156
Detailed Programme	21 427
Programme at a Glance	14 050
Programme	11 356
Dates & Prices	9 585

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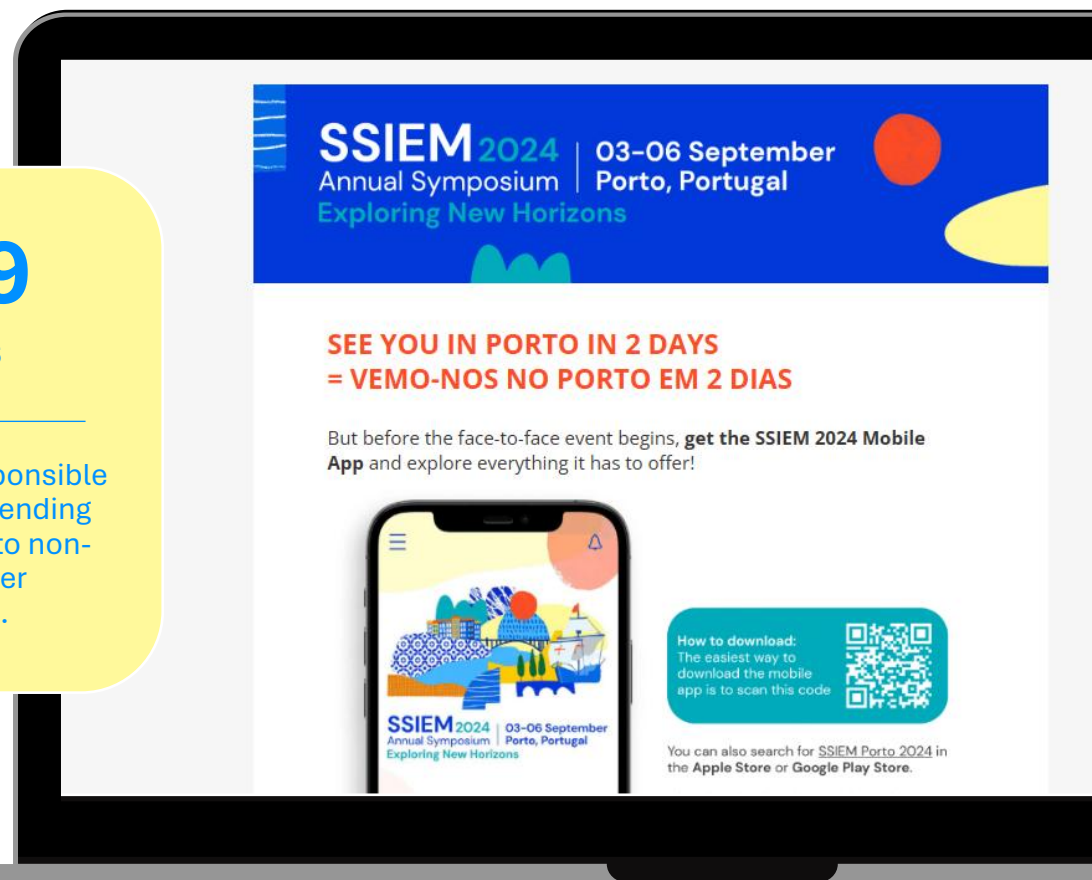
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NEWSLETTERS

1 199

Contacts

Leading is only responsible for handling and sending communications to non-SSIEM member participants.



Newsletters - performance:

Name	Date	Open rate	Click rate
NL 1 - First updates	25 May, 2024	54.20%	19.08%
NL 2 - 3 months left until #SSIEM2024	5 June, 2024	58.33%	24.24%
NL 3 – Early Birds Deadline	27 June, 2024	47.73%	12.88%
NL 4 – Final Programme	7 August, 2024	49.81%	15.87%
NL 5 – App and last importante information	31 August, 2024	62.47%	17.51%

Data collected from the **Sender Platform** - 28 Oct 2024

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S O C I A L M E D I A



The first post created by Leading was published on March 22, 2024, and the latest on October 06, 2024



44
Posts produced

31
Posts planned

Impressions
32 158

Reactions
1 377

Unique views
16 295

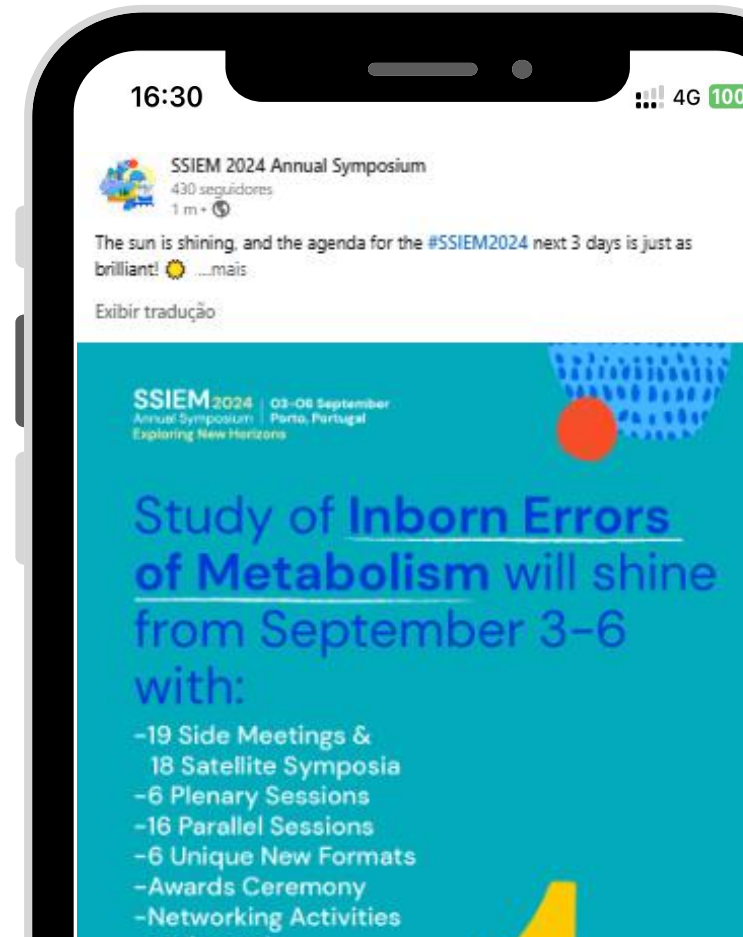
Comments
13

Clicks
4 934

Shares
37

Followers
430

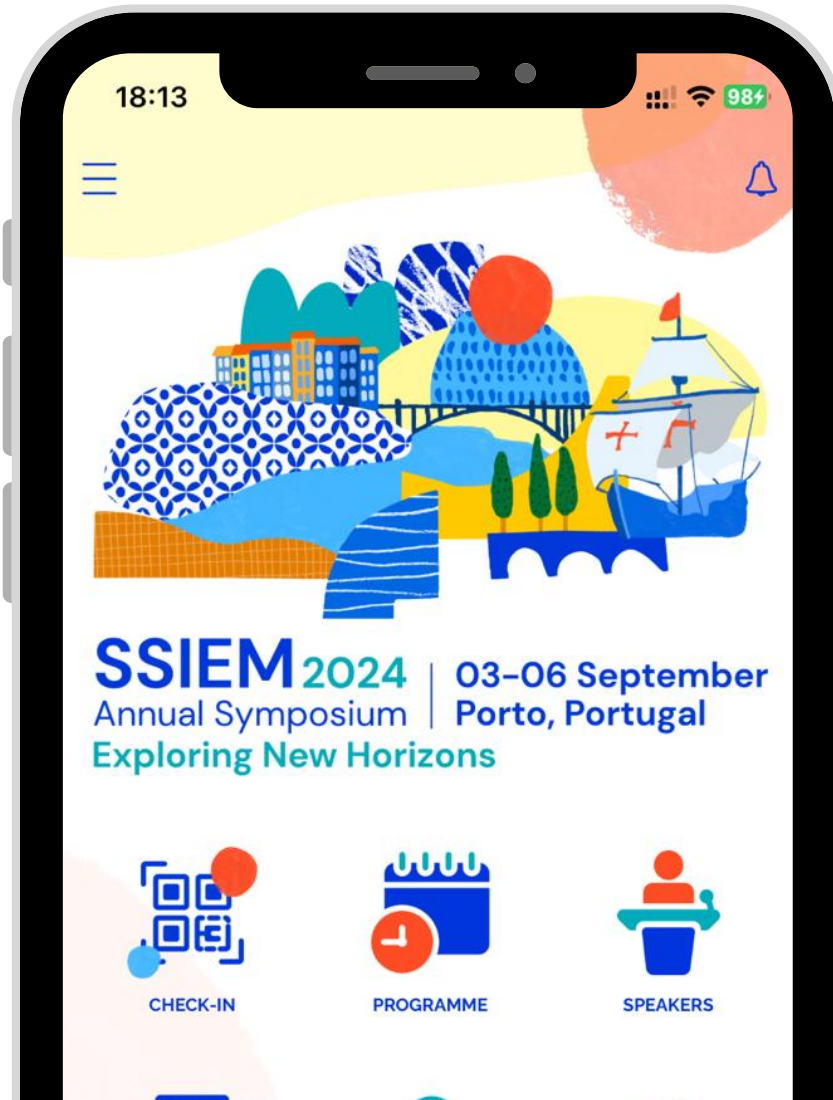
Best performance Post:
Programme Highlights: day 3 and 4
| published on 03/10/2024



Data collected from the LinkedIn - 25 Oct 2024

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MOBILE APP



+ 2.000 PARTICIPANTS
USING THE MOBILE APP
AVERAGE USAGE PER
PARTICIPANT - 74
MINUTES
1.266 SESSION RATINGS
RECEIVED

79
Notifications

SUSTAINABILITY

Programme book and signage in recycled materials
Refood programs – 690 Kg
Reduced use of plastic



SOCIAL IMPACT

KASTELO

Running/Walk With Purpose



Thank you!



PAG session in SSIEM 2024

PAG Session program structure involved both local and international association:

- Barbara Yu – President Citrin Foundation (barbarayu@citrintfoundation.org)
- Raquel Marques – President of Sanfilippo Portugal, Vice-President RD Portugal (sanfilippoportugal@gmail.com)
- Kirsty Hoyle - Metabolic Support UK, CEO (kirsty@metabolicsupportuk.org)
- Laura Smith Van Carroll - Metabolic Support UK, Head of Insight and Advocacy (laura@metabolicsupportuk.org)
- Vanessa Ferreira - President of the Portuguese Association for CDG (APCDG) (sindromeCDG@gmail.com)

•
And the SSIEM representative as session coordinator of the program.

PAG session Present and Future



Present

- Small number of PAG involved initially but others were called to make interventions
- Program proposed by the PAG adjusted to a broader scope
- SSIEM sponsored :
 - Full registrations for one patient representative (director)
 - Speakers registrations

Future:

- Clearly outline the purpose of the session: does the SSIEM just offers a stage for the PAG and maintain some guidance on the program.
- Mainly local PAG?
- Call other players? Eurordis, MetabERN Patients representatives
- Keep this sponsoring level?
- Time slot





Parallel session or main session - pros and cons:

Main session:

Pros:

Allows larger audience as it does not compete with other parallel sessions.

- Round table/ mixed panel discussions regarding a hot topic

Cons:

Reduces time slot allocated for the PAG

Reduces time slot allocated for the main scientific session.

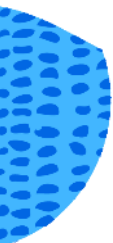
Scientific content from the PAG session is variable.





Engagement Initiatives for **Young Investigators**

- ❑ **Parallel Sessions for Young Investigators:** Sessions focused on topics relevant to early-career researchers, such as scientific publishing about IEM;
- ❑ **Mentorship Program:** Opportunities for young investigators to connect with “senior” young investigators for guidance and networking;
- ❑ **Young Scientists in Congress Organization:** enable young investigators to organize parts of the SSIEM;





Engagement Initiatives for **Young Investigators**

- ❑ **Do not schedule parallel sessions** during the **poster session**;
- ❑ **Enable Automatic Subtitles:** Provide automatic subtitles for oral presentations to support presenters who are less fluent in English;
- ❑ **Awards and Honorable Mentions:** Recognize the scientific publications of young investigators with awards and honorable mentions;
- ❑ **Social Program- City Treasure Hunt:** Organize a treasure hunt around the city to help participants explore the local area and meet new people in a fun, interactive way.

