

The screenshot shows the top navigation bar with a search box on the left and the text 'ABSTRACT SUBMISSION' and 'Call for abstracts' on the right. Below this is a blue 'HOME' button. The main content area is split into two columns. The left column is a large empty white box. The right column contains two buttons: 'Registered Users' with a 'Login' button below it, and 'Create an Account' with a 'GO' button below it. Below these is a 'CALENDAR' section with a table of key dates.

CALENDAR	
Call for abstracts	01 February
Deadline (Midnight GMT)	19 April
Decision	01 June 2020

**SSIEM**

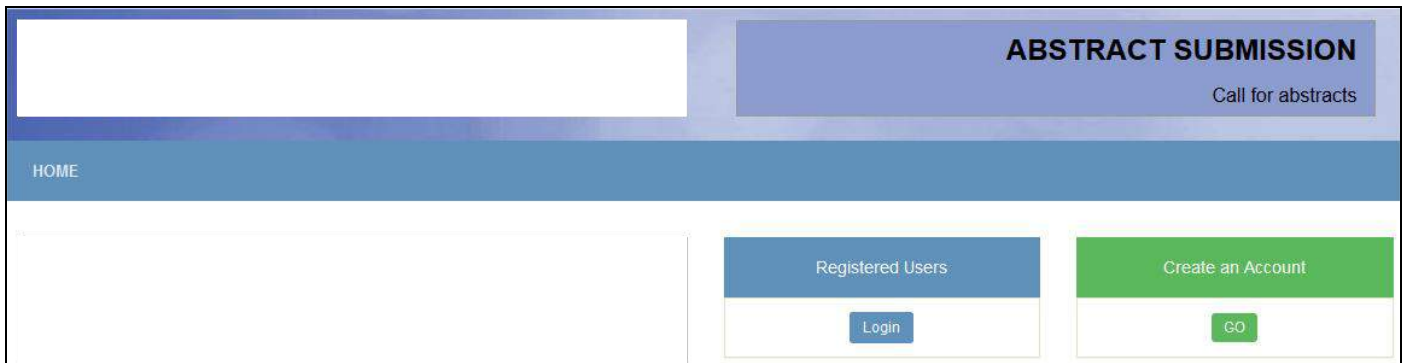
**Society for the**

**Study of Inborn Errors of Metabolism**

# **GUIDE FOR REVIEWER**

**January**

Login at [www.symposiumabstracts.com/ssiem](http://www.symposiumabstracts.com/ssiem)



The screenshot shows the top navigation bar of the website. On the right side, there is a blue header with the text "ABSTRACT SUBMISSION" and "Call for abstracts" below it. On the left side, there is a white search bar. Below the search bar, there is a blue navigation bar with the word "HOME" on the left. Below the navigation bar, there are three main content areas. The first is a large white box. The second is a blue box labeled "Registered Users" with a "Login" button below it. The third is a green box labeled "Create an Account" with a "GO" button below it.



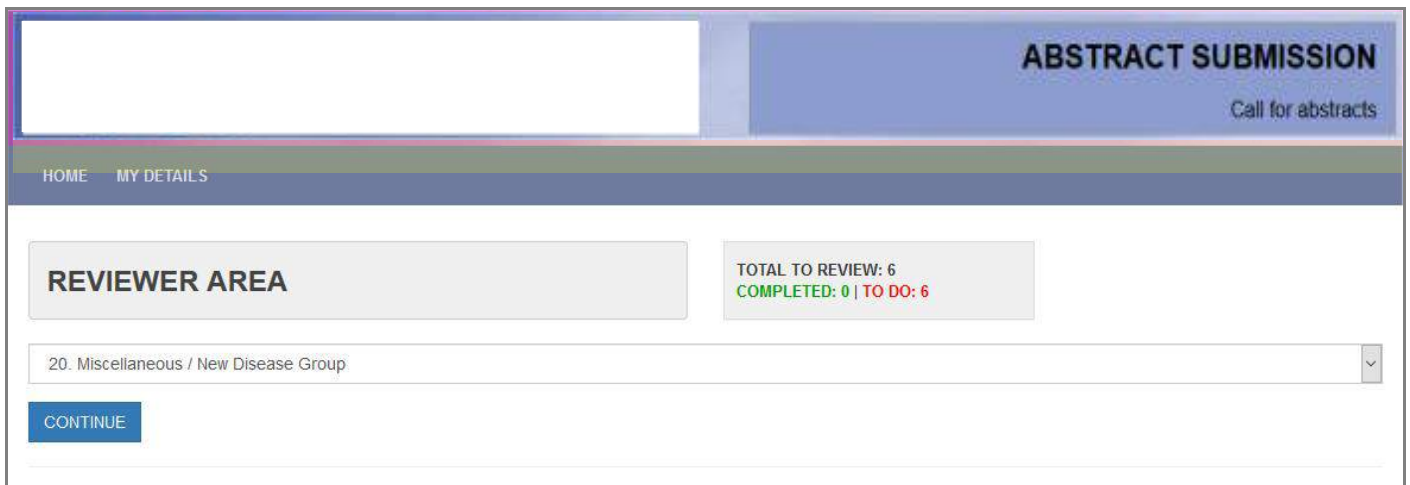
Go to Reviewer Area



The screenshot shows the user dashboard after login. The top navigation bar is the same as in the previous screenshot. Below it, there is a blue navigation bar with "HOME" and "MY DETAILS" on the left. Below the navigation bar, there are three main content areas. The first is a white box with a blue button labeled "REVIEWER AREA", which is highlighted with a red border. The second is a white box with a green button labeled "REVIEWER GUIDE". The third is a white box with the text "TOTAL TO REVIEW: 6" and "COMPLETED: 0 | TO DO: 6" below it.



## Reviewer Area – select the category you have been allocated



ABSTRACT SUBMISSION  
Call for abstracts

HOME MY DETAILS

REVIEWER AREA

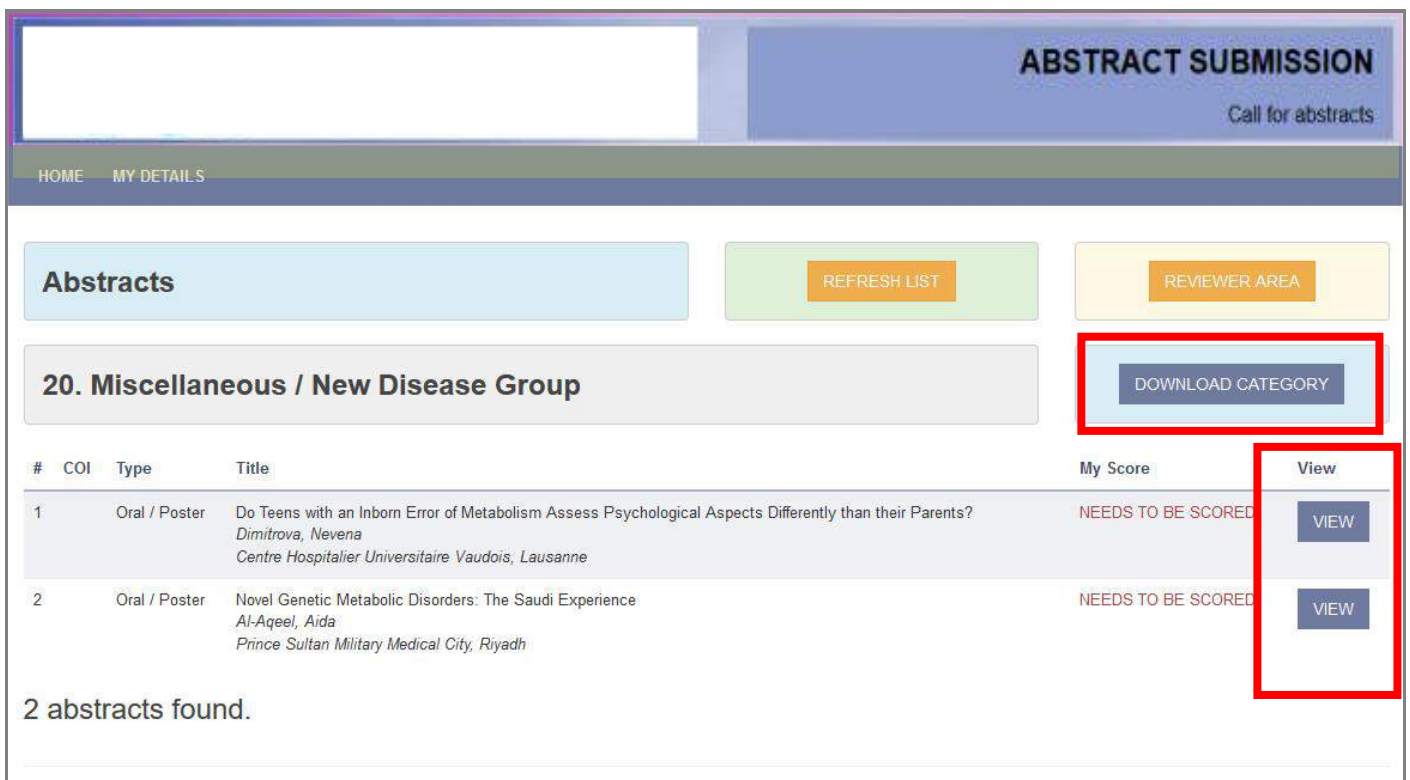
TOTAL TO REVIEW: 6  
COMPLETED: 0 | TO DO: 6

20. Miscellaneous / New Disease Group

CONTINUE



You can download your abstracts for viewing offline, but you will need to return to this page to View and Score online



ABSTRACT SUBMISSION  
Call for abstracts

HOME MY DETAILS

Abstracts

REFRESH LIST

REVIEWER AREA

20. Miscellaneous / New Disease Group

DOWNLOAD CATEGORY

#	COI	Type	Title	My Score	View
1		Oral / Poster	Do Teens with an Inborn Error of Metabolism Assess Psychological Aspects Differently than their Parents? <i>Dimitrova, Nevena</i> <i>Centre Hospitalier Universitaire Vaudois, Lausanne</i>	NEEDS TO BE SCORED	VIEW
2		Oral / Poster	Novel Genetic Metabolic Disorders: The Saudi Experience <i>Al-Aqeel, Aida</i> <i>Prince Sultan Military Medical City, Riyadh</i>	NEEDS TO BE SCORED	VIEW

2 abstracts found.



ABSTRACT SCORING

BACK TO LIST

NEXT ABSTRACT

Abstract Type

ORAL OR POSTER

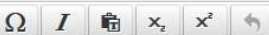
An oral abstract will be delivered as a presentation at a specified session within the programme. Authors agree that accepted abstracts may be presented as posters if necessary due to shortage of time.

Subject category

20. Miscellaneous / New Disease Group

Abstract Title

Format ▾



Do Teens with an Inborn Error of Metabolism Assess Psychological Aspects Differently than their Parents?

SUBMIT TITLE CHANGES

MY SCORE

- 0 - No score- I am a member of this group
- 1 - reject
- 2 - e-poster
- 3 - poster
- 4 - oral presentation / poster
- 5 - oral presentation
- 6 - latest result

If you have time please make english corrections

- No corrections required
- I have made english corrections
- English needs to be corrected

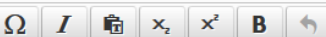
Additional comments (Optional - Max 250 chars)

Brief comments - if any ...

SUBMIT

Abstract Text

Format ▾



**BACKGROUND:**  
Inborn errors of metabolism (IEM) often require medical monitoring along with a restrictive diet and/or drug treatment. As a life-long medical condition, these constraints likely affect various aspects related to psycho-social functioning in patients and their families, such as quality of life, mental health, and coping strategies. However, it remains unknown whether affected children differ in their perception of these psychological aspects compared to their parents.

**METHODS:**  
Participants included 10 IEM-diagnosed teenagers ( $M_{age}=15$  years, range: 14-17; 7 boys) along with one of their parents. We used a self-report vs. parent-report versions of the Phenylketonuria Quality of Life Questionnaire in order to assess health-related quality of life and the Strengths and Difficulties Questionnaire in order to assess teenager's mental health. Last, we used the self-reported Cognitive Emotion Regulation Questionnaire in order to assess individual coping strategies.

**RESULTS:**  
Teen-aged children did not differ from their parents in terms of individually assessed health-related quality of life ( $p=.661$ ). Concerning mental health, the only difference appeared to be in teenagers self-reporting more conduct problems ( $M=3.1$ ,  $SD=1.97$ ) compared to their parents ( $M=1.22$ ,  $SD=1.56$ ;  $t(17)=2.83$ ,  $p=.036$ ). Last, in respect to coping strategies, we found that parents scored significantly higher on all subscales, except on positive refocusing ( $p=.391$ ) and on putting into perspective ( $p=.149$ ).

**DISCUSSION:**  
Aspects related to both physical and psychological evaluation were perceived in similar ways by IEM-diagnosed teenagers and by their parents. However, parents showed more coping strategies, both adaptive (e.g., acceptance, refocus on planning, positive reappraisal) and maladaptive (e.g., self-blame, blaming others, rumination, catastrophizing). Special care should be given to parents in order to help them decrease maladaptive coping and to teenagers to increase adaptive coping.



