

**Center of Excellence Criteria & Application**

Dear applicant,

Thank you for your interest in becoming a Rett Syndrome Center of Excellence (COE).

Clinics designated as COE are distinguished by providing excellent medical care and consultation, advancing clinical and translational research, and serving as thought leaders in topics related to Rett Syndrome treatment and research.

As funds allow, the International Rett Syndrome Foundation (IRSF) intends to provide limited financial support to clinics that achieve COE designation to support a coordinator. Beginning in January 2022, all COEs will be expected to enter data into the IRSF Rett Clinical Disease Registry, which takes the place of the longitudinal NIH RDCRN Natural History Study that concluded July 31, 2021.

Applications for COE designation are reviewed and approved by IRSF Executive leadership.

Minimum requirements for 2022 designation and instructions for completion/submission are listed below. Feel free to contact us with any questions.

**Sincerely,**

***Melissa Kennedy, M.H.A.***

Chief Executive Officer

International Rett Syndrome Foundation

***Dominique Pichard, M.D.***

Chief Science Officer

International Rett Syndrome Foundation

**Application Steps:**

Please complete the following information and submit to Melissa Kennedy at [mkennedy@rettsyndrom.org](mailto:mkennedy@rettsyndrom.org) by x/x/2022.

“Yes” and “No” checkboxes in the application are clickable. Once complete, save and submit by the due date above.

After review, you will be notified of the designation decision by x/x/2022.

**Clinic Name and Contact Information for Publication:**

Institution name:

Clinic name:

Address:

Medical Director:

Clinic Coordinator:

Contact person Email:

Phone:

Website:

**Clinic Operations and Patient Volume**

Rett Syndrome Clinic Operation:

Number of Days per Week *or* Number of Days per Month:

Multidisciplinary: Yes or No

Provide additional comments on Rett clinic structure:

Age range of patients seen:

Unduplicated count of Rett patients seen annually:

Unduplicated count of NEW Rett patients seen annually:

NEW = Not seen at clinic prior

Insurance information:

Accept Medicaid?

Your State Only?

Accept Private Insurance?

Sliding Scale Available?

Medicare?

**Rett Centers of Excellence Criteria**

Minimum requirements for Rett Centers of Excellence designation are as follows:

1. The clinic has the following staff:
   1. Physician Director who oversees all clinical services and has expertise in the diagnosis and medical management of Rett syndrome across the lifespan using the current best practices. The current best practices include the “Core Care Assessments” listed in table below.
   2. A coordinator of services and referrals who is the main contact for families being served by the clinic. This person will submit/ensure completeness of data into the IRSF Rett Clinical Disease Registry.
2. An array of services and/or referrals are available, which cover the needs of individuals with Rett syndrome throughout the lifespan.
   1. The services and referrals required to complete the assessments listed in the “Core Care Assessment” table are the minimum expectation. “Supplemental Care Services” are optional members of the Rett Clinic.
3. The Clinic Director will attend annual in-person network meeting and/or clinical presentation forums.
4. The clinic demonstrates involvement in clinical research and clinical trials.
5. The clinic agrees to initiate data submission to the Rett Clinical Disease Registry on all patients with Rett syndrome seen in the clinic.
6. The clinic encourages family participation in annual “Pediatric Integrated Care Survey (PICS)” administered by IRSF.

Future activities required to renew funding from IRSF will include:

1. Submission of patient-level data to the IRSF Rett Clinical Disease Registry.
2. Identification and adherence to criteria that assess transition to adult care.

**COE Application Completion Instructions:**

* For the items listed above, please provide a narrative that explains how the center meets the minimum requirements for COE designation.
* Review the tables that follow and indicate “YES” or “NO” for each criterion.
* “YES” and “NO” selection boxes are clickable. Once answers are recorded, save with a new document name and return to Melissa Kennedy [mkennedy@rettsyndrome.org](mailto:mkennedy@rettsyndrome.org) by x/x/2022.
* Please contact Melissa Kennedy should you have questions during the process.

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| --- | --- | --- | --- |
| **Core Care Assessments** | **YES** | **NO** | **Primary Care Guidelines/**  **Anticipated future measurement areas for COE designation** |
| General medical evaluation including labs |  |  | Current medications and allergies, weight, head circumference, Tanner stage, lab evaluations |
| Cardiology assessment |  |  | Check QTc interval with EKG; if abnormal, refer to Cardiology |
| Neurologic assessment including neurodiagnostics and EEG |  |  | Screen for presence of seizures and spells suspicious for seizures  Record description and frequency of seizures  Encourage patient to follow-up with neurologist routinely; every 6 months if treated for seizures  If patient weight fluctuates (more than 10-20%), request neurologist to consider adjusting anti-convulsant doses accordingly |
| Orthopedics |  |  | Estimate curvature of spine. Recheck every 6 months if scoliosis present; refer to Orthopedics if > 20 degrees  Screen for abnormal hip abduction (ROM) and leg length  Screen for contractures and use or need of devices to prevent them (AFOs and splints)  Discuss risk of fractures due to osteopenia  Screen for needs and use of mobility aids |
| Genetic testing |  |  | Counsel on results and refer to genetic counselor as needed for additional counsel or explanation |
| Developmental assessment |  |  | Documentation of baseline, gains and losses of milestones  Fine motor - hand use: raking grasp, pincer grasp, rake, holding cup or spoon  Gross motor: sitting, standing, and walking  Language: coo, babble, laugh, words |
| Behavioral assessment |  |  | Screen for symptoms of anxiety and depression such as withdrawal, screaming, irritability  Inquire about sensory processing difficulties |
| Communication assessment |  |  | Screen communication methods used by family and school: eye pointing, vocalizations, switches, iPad, eye-gaze device |
| GI assessment |  |  | Review feeding methods, appetite, chewing ability, choking and length of feeding time |
| Educational assessment/IEP |  |  | Review for the presence of current IEP (see info on RettSyndrome.org)  Documentation of therapies (type and frequency) |
| Pain assessment |  |  | Discuss higher pain threshold and describe individual’s response to pain. |
| Breathing assessment |  |  | Screen for awake disordered breathing (hyperventilating, breath-holding, color change), and air swallowing |
| Mobility assessment |  |  | Screen for needs and use of mobility aids |
| Nutritional assessment |  |  | Assess calories, fluids, calcium and vitamin D intake |
| Sleep assessment |  |  | Review sleep initiation, staying asleep, snoring or coughing, and frequency of nocturnal interventions by caregivers  Review safety of bedroom. |
| Social needs assessment |  |  | Assess for family stress (financial, social, fatigue) |

|  |  |  |  |
| --- | --- | --- | --- |
| **Supplemental Services** | **YES** | **NO** | **Comments:** |
| PM&R Therapies |  |  |  |
| Speech/AAC |  |  |  |
| Gynecology |  |  |  |
| Social Work |  |  |  |
| Endocrinology |  |  |  |
| Psychiatry |  |  |  |
| Nutritionist |  |  |  |
| Pulmonary |  |  |  |
| Geneticist |  |  |  |
| Epilepsy |  |  |  |
| Dental |  |  |  |
| Palliative Care | ☐ | ☐ |  |

**Minimum Requirements Narrative:**

**Comments:**

We welcome your comments and feedback. Feel free to use the area below and additional space as needed.