

Element	Criteria	Description	Information collected through application or additional documentation	Available points	Required	Additional notes
Clinical experience	Number of patients treated	The HI Center has a history of treating HI patients.	1. Total # of unique HI patients treated since HI Center was formed 2. Date center was formed 3. Total # of unique HI patients treated in the last 12 months (this includes active patients who have been seen, contacted, or consulted with)	5	Yes	It will be required for centers to provide the number of patients treated, extra points are available in E.2 based on volume.
Clinical experience	Level of experience with patients	The Center has extensive experience treating HI patients.	(Information collected as part of E.1)	4	No	Points will be earned if a center has examined 50 HI patients in the last calendar year and a minimum of 100 total patients since the center was founded. If a center does not currently meet the volume of patients necessary for this criterion, the applicant must provide some justification on how the center can assure sufficient patient volume to establish and maintain expertise. Any submission that does not meet the volume criteria will be evaluated by CHI in consultation with the COE
Integrated multi-disciplinary team	Dedicated multi-specialty pediatric hospital system	The center must have an affiliation with a health system that cares for pediatric patients with established multi-specialty services, such as, but not limited to, cardiology, neurology, gastroenterology, and ophthalmology.	Name of hospital	2	No	

Directorship	Dedicated director	<ol style="list-style-type: none"> 1. The director (or co-directors) is responsible for the administration of the HI Center; AND 2. The director has a commitment to providing comprehensive care for individuals with HI; AND 3. The director is a medical doctor with medical board certification in their country of clinical practice in a specialty related to one or more aspects of HI (such as endocrinology); AND 4. The director is responsible for ensuring that the key roles of the HI Center primary team (as described in B.1) are filled by individuals with the appropriate qualifications. 	<ol style="list-style-type: none"> 1. Director's name 2. Director's email 3. Director's phone number 4. Director's area of medical specialty 5. A link to the center's website with posted information about the director's association with the center 6. Director's CV 7. Briefly describe director's HI relevant experience 	5	Yes	If the director leaves the center while the COE designation is active, CHI must be notified of the change in leadership. If a center fails to do so, they risk losing the current designation.
Directorship	Assistant director	<ol style="list-style-type: none"> 1. An assistant director (or equivalent leadership role) works closely with the director to oversee the administration of the HI Center; AND 2. The assistant director assumes leadership responsibility of the center in the director's absence; AND 3. Assistant director has a commitment to providing comprehensive care for individuals with HI 	<ol style="list-style-type: none"> 1. Assistant director's name 2. Assistant director's email 3. Assistant director's phone number 4. Assistant director's area of medical specialty 5. A link to the center's website with posted information about the assistant director's association with the center 6. Assistant director's CV 7. Briefly describe assistant director's HI relevant experience 	3	No	The role of the Assistant Director does not need to be filled by an MD, but the AD should be prepared and capable of assuming temporary leadership of the Center if the Director is no longer able to do so.

Integrated multi-disciplinary team	Primary team	<p>Dedicated staff in the following clinical areas (or equivalent international specialists) must be part of the primary team that works collaboratively to determine treatment plans for HI patients.</p> <p>1. Physician with significant HI clinical/ research experience (e.g. endocrinologist, metabolic specialist, diabetologist)</p> <p>2. Surgeon</p> <p>3. Neonatologist/ Pediatrician with neonates, infants, and children with HI</p> <p>4. Nurse/ Nurse clinical coordinator/ HI Nurse</p> <p>Note: This criteria cannot be met if rotating general department staff clinicians provide services in lieu of</p>	<p>For each of the 4 specialists:</p> <p>1. Name</p> <p>2. Credentials (area of specialty and degree)</p> <p>3. Specialist CV</p> <p>4. Briefly describe each member's HI relevant experience</p>	5	Yes	<p>If any of these primary team members leave the center while the COE designation is active, CHI must be notified of the change in primary team member. If a center fails to do so, they risk losing the current designation. A COE is expected to have a minimum of four specialists associated with the center, it is possible that one of these specialists also serves as the Director or Assistant Director.</p>
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Clinical experience	Surgical expertise	Surgeries are performed by a surgeon with clearly documented recent experience in pediatric pancreatectomies.	<ol style="list-style-type: none"> 1. Surgeon name and credentials (if not included as part of B.1) 2. Number of pancreatectomies performed by the surgeon in the past 5 years. 	5	Yes	<p>Points will be earned if the center performed a minimum of 20 surgeries in the past 5 years.</p> <p>If a center does not currently meet the volume of patients necessary for this criterion, the applicant must provide justification on how the center can assure sufficient patient volume to establish and maintain expertise. The population of the center's country/ catchment area will also be taken into consideration. Any submission that does not meet the volume criteria will be evaluated by CHI in</p>
Clinical experience	Types of surgical expertise	The HI Center has demonstrated surgical experience for the different types of HI surgeries.	<ol style="list-style-type: none"> 1. Number of focal surgeries in the past 5 years 2. Number of diffuse surgeries in the past 5 years 3. Number of atypical surgeries in the past 5 years 	4	No	

Integrated multi-disciplinary team	Extended team	<p>The integrated multi-disciplinary team will include broader participation of dedicated clinicians who establish a relationship with the primary team to determine treatment plans for HI patients. This should include at least 8 of the following specialties, but is not limited to the following specialties or international equivalents:</p> <ol style="list-style-type: none"> 1. Certified diabetes education 2. Diet/ nutrition/ feeding therapy 3. Developmental pediatrics 4. Gastroenterology 5. Genetic counseling/ genetics 6. Neurology 7. Nursing/ advanced practice nursing 8. Pathology 9. Physical/ occupational/ speech therapy 10. Psychiatry/ psychology 11. Radiology/ nuclear medicine 	Staff list with names and credentials (degrees)	5	Yes	Applicant will receive full points if center identifies specialists or team members in 8 of the 12 listed areas.
Integrated multi-disciplinary team	Essential team succession plan	The HI Center has a documented succession plan if any of the key specialists leave or are no longer associated with the center. This includes, but is not limited to the HI specialist endocrinologist, surgeon, pathologist, and radiologist.	Succession plan documentation	2	No	
Clinical experience	Inpatient care	<ol style="list-style-type: none"> (1) Primary team from HI Center provides direct patient care in the hospital setting; AND (2) HI Center team provides consultation virtually to HI patients' home pediatrician, endocrinologist (or equivalent) when patient is admitted; OR (3) Pre-arranged established co-management of HI patient between dedicated facilities 	<ol style="list-style-type: none"> 1. Description of inpatient care and inpatient SOP; OR 2. Co-management protocol; OR 3. Letter of support from hospitals that work with the HI Center on a consistent basis 	5	Yes	Co-management protocols must include identification of participating institutions covered under the agreement.

Care coordination	Care coordination staff	The HI Center has dedicated staff to address transfer of care from hospital to hospital, hospital to home, home to hospital, and other relevant referral management for patients. The staff member has a public direct phone number posted on the website.	Link to care coordination staff contact information (phone number) on HI Center website	5	Yes	
Care coordination	Transitional care	The HI Center has a clearly defined documented process for transitioning young adults from a pediatric to adult endocrinologist OR proof of willingness to provide continuous care.	Transition standard operating procedure (SOP) which must include either: 1. Documentation for transition process; OR 2. If the center provides continuous care to HI patients, regardless of age, documentation of process and willingness to provide continuous care	4	No	
Evidence-based care delivery	Evidence-based care	The HI Center utilizes standard operating protocols/guidance for recognizing, evaluating, and managing persistent hypoglycemia based on evidence and/or consensus within the multidisciplinary team.	1. Hypoglycemia guidelines (name, source or written policy) used by HI Center 2. If affiliated with a hospital, must submit nursery/NICU policy/pediatric inpatient guidelines regarding hypoglycemia definition and management	5	Yes	Acceptable standards are PES or more stringent guidelines for evaluating and managing hypoglycemia. If a center indicates they are following PES guidelines, reviewers will easily be able to verify that this criteria is met. If a different set of guidelines is being followed, they will be submitted to our scientific advisor endocrinologists for a blind review to determine if it meets the minimum standard. Our understanding is that these guidelines are not just for neonate or nursery standards, but also for inpatient pediatric visits, and should be in place for all centers to follow.

Clinical experience	Telemedicine	HI Center offers services via telemedicine.	Description of use of telemedicine	3	No	
Clinical experience	Genetic testing arrangements	Rapid genetic testing is available either onsite or through established arrangement.	1. Description of rapid genetic testing facility, either: A. Description of onsite facility; OR B. Documentation or description of genetic testing agreement with an outside entity; AND 2. Average time of turnaround; AND 3. Proof of the lab's national (or equivalent) accreditation	5	Yes	
Clinical experience	Genetic analysis expertise	Genetic testing performed on HI patients is interpreted by a medical geneticist with clearly documented recent experience with HI genetics.	1. Medical geneticist name and credentials (if not included as part of B.1) 2. Number of HI genetic tests interpreted in the past 12 months	5	Yes	
Clinical experience	Pathology arrangements	Rapid pathology testing is available either onsite or via established arrangement.	1. Description of onsite pathology process (including frozen section and rapid histopath); OR 2. Description of institutional partner's onsite pathology process; AND 3. Clear documentation that access, communication, and collaboration between histopathology and clinical teams is available during surgery regarding the interpretation of findings	5	Yes	The center should document how they use frozen sections during surgery to confirm histopathology.
Clinical experience	Pathology expertise	Pathology is interpreted by a pathologist with clearly documented recent experience with HI pathology.	1. Pathologist name and credentials (if not included as part of B.1) 2. Number of HI pathology tests interpreted in the past 12 months	5	Yes	

Clinical experience	Advanced technologies arrangements	F-DOPA positron emission tomography (PET) is available onsite or via established co-management arrangement	<ol style="list-style-type: none"> 1. Certificate/ license from governing body allowing use of F-DOPA for HI detection; 2. If co-management arrangement, need the certificate of the facility with PET capability unless that facility is already recognized as a HI COE; AND 3. If an arrangement requires a child to be transported to a different facility, a description of the pediatric expertise available at the facility is necessary. This should include the process to transport the child to and from the facility, staff available to manage the child during the scan, and the process of communication/collaboration between the two institutions to interpret the results; AND 4. If co-management arrangement, need 	5	Yes	
Clinical experience	Imaging expertise	Imaging performed on HI patients is interpreted by a radiologist with clearly documented expertise with advanced HI imaging techniques.	<ol style="list-style-type: none"> 1. Radiologist name and credentials (if not included as part of B.1) 2. Number of F-DPOPA PET imaging studies radiologist has completed in the past 12 months in children with HI under the age of 2 3. Number confirmed surgical correlation of pre-operative reading 	5	Yes	

Clinical experience	Outpatient	Multidisciplinary or extended team provides care in the outpatient setting. This may include, but is not limited to the following specialties or international equivalents: 1. Endocrinology 2. Certified diabetes education 3. Gastroenterology 4. Neurology 5. Physical/ occupational/ speech therapy 6. Psychiatry/ psychology 7. Developmental pediatrics 8. Dietician	Description of outpatient services	5	Yes	You must provide at least 5 of the services to receive the points.
Inter-facility	Transfer facilitation	The HI Center has an established acceptance mechanism for HI patients from around the world who require alternate pricing.	Description of process or SOP	3	No	
Inter-facility	Patient care	Members of HI Center team are available for consultation to other physicians by phone (or other medium) regarding HI patient who does not otherwise have access to HI Center.	1. Estimate the number of times a professional outside of your institution has requested that a member of the Center's primary team provide a consultation in the past 12 months; and 2. Estimate the number of times a member of the Center's primary team provided a consultation in the past 12 months	5	Yes	
Quality and patient experience	Quality metrics	The HI Center has a protocol to maintain quality metrics regarding HI patient outcomes related to care delivery.	Provide protocol description or list of quality measures with descriptions or definitions	5	Yes	
Quality and patient experience	HI experience	The HI Center can provide details for key quality metrics related to HI patient outcomes.	Provide current benchmarks and performance for key measures	4	No	
Quality and patient experience	Performance improvement	The HI Center demonstrates at least one instance where quality data was incorporated to improve care delivery.	Provide description of when quality data metrics were used for improved care delivery	3	No	

Quality and patient experience	Patient satisfaction survey	The HI Center will maintain quality metrics regarding HI patient/family satisfaction related to care delivery at the HI Center.	1. Quality metric HI patient/family satisfaction documentation 2. Text of the survey used to collect patient/family satisfaction	5	Yes	
CHI engagement	HI Global Registry referral source	Can provide proof that center staff actively refers HI patients to HI Global Registry.	1. Description of patient referrals to HI Global Registry and link (or upload additional proof) 2. Upload for flyer, website link, screenshot, or mailer (including e-mail)	5	Yes	Patients are not required to participate in the Registry to meet this required factor, but clear referral process must be in place.
HI-relevant research	Active HI research	Researchers affiliated with the HI Center must be actively engaged in current HI research (e.g. basic science, natural history, treatment, clinical trials etc.)	Current research information (i.e. title, funding, source, start date, end date, collaborator name, collaborator institution, and link or description of study)	5	Yes	
HI-relevant research	Interventional clinical trials	The HI Center has participated in an HI relevant clinical trial in the previous 5 years.	Past clinical trial information (i.e. title, funding, source, start date, end date, collaborator name, collaborator institution, and link or description of study)	Up to 5	No	Centers will earn 1 point per trial up to 5 total points, or the center can earn 2 points if the center demonstrates capacity and
HI-relevant research	Clinical trials	If the HI Center is not currently involved in clinical trials, the HI Center has the capacity and willingness to participate in HI relevant clinical trials.	1. If the Center is not currently involved in a clinical trial, list any non-HI specific trials the Center participated in; OR 2. List any clinical trials the division or department participated in; OR 3. Provide description to demonstrate Center's capacity to participate in a clinical trial	2 (included in G.2)	No	
Inter-facility	Research	Members of HI Center team participates in HI-relevant project with researchers from a facility other than their own within the last five years.	Study or project information (i.e. title, funding, source, start date, end date, collaborator name, collaborator institution, and link or description of study)	5	Yes	
HI-relevant research	HI publications	Researchers affiliated with the HI Center must have published an HI relevant article in a peer-reviewed medical journal within 3 years of application	Publication information (i.e. title, authors, journal, date of publication, link to publication)	5	Yes	

Continuing education	Internal staff	HI Center staff communicates on HI relevant topics on at least a quarterly basis.	1. Description of communication channel or opportunities to share information as a larger HI Center team 2. If this includes a formal event, please provide event information (i.e. event name, sponsoring organization, date, title of presentation, link) 3. Meeting documentation or agenda (optional)	5	Yes	
Continuing education	Local and regional clinicians	HI Center staff educates local, hospital-affiliated, or regional clinicians on HI relevant topics at least semi-annually or more often.	1. Event information (i.e. event name, sponsoring organization, date, title of presentation, link) 2. Meeting documentation or agenda (optional)	5	Yes	
Continuing education	National or international conferences	HI Center staff educates national or international clinicians on HI relevant topics at least annually or more often.	1. Event information (i.e. event name, sponsoring organization, date, title of presentation, link) 2. Meeting documentation or agenda (optional)	5	Yes	
CHI engagement	SAG/ CRN member	Qualified representative from HI Center agrees to serve on the CHI Scientific Advisory Group or in the Collaborative Research Network (CRN) and regularly responds to CHI requests for assistance, clinical input, or guidance on HI-related issues.	Name of SAG/CRN participant or individual willing to serve on SAG	5	Yes	
CHI engagement	Educational event participation	Member of HI Center has participated as a participant, presenter, panel member, or sponsor of a CHI educational event in the last 3 years.	Event name and role (in the application we will provide a list of CHI sponsored education events including family conferences)	5	Yes	

CHI engagement	Other CHI program participant	Participates as presenter, panel member, sponsor, committee member or other active role in CHI program not specifically mentioned in J.2	Description of participation	2	No	This could include, but is not limited to, participation in CHI organized educational events, the Sugar Soiree, million dollar bike ride, specialized committee, HIGR advisory committee, or others.
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Elements	Number of questions	Number of points	Points needed for designation
Total for all elements	39	174	155
Required elements	27	135	135
Optional (All)	13	41	20
Optional- Up to 5	1	Up to 5	N/A
Optional- 4 points	4	16	N/A
Optional- 3 points	4	12	N/A
Optional- 2 points	4	8	N/A

This spreadsheet provides the criteria descriptions and points associated with the HI Centers of Excellence application. Column A "Application Question" provides the question number associated with each element for the online application. Any Hyperinsulinism or Hypoglycemia Center (referred to in the document as "Center") can submit an application to receive the HI COE designation if they have a focus on hyperinsulinism treatment and research.

Completed applications will be evaluated and scored by CHI staff. A Center needs to earn a total score of 155 or higher to earn the designation. Of those points, 135 need to be earned through the 27 required elements and the remaining 20 points can be earned through any of the other elements.

If you have any questions, please contact Tai Pasquini, Research and Policy Director, via email toasquini@congenitalhi.org or phone 973-842-7559.