

Region 4 Genetics Collaborative Base Funding Logic Model

Assumptions

1. Collaboration among stakeholder groups, Region 4 states, across regions, and with national partners will improve access to genetic services, expertise, and information in the context of the medical home for children with heritable disorders and their families

2. Effective follow-up for children with heritable disorders provides “just in time information” to the child’s family and medical home. This includes children identified through newborn screening, early hearing detection, birth defect registries, CSHCN, and early intervention programs.

3-7. Children with heritable disorders who have access to genetic services, expertise and information within the context of a medical home will have better health outcomes and quality of life. *In order to successfully establish medical homes for children with heritable disorders the following conditions must exist:*

3. Families and providers must be aware of how the medical home model improves care and outcomes for children with heritable disorders

4. Care coordination must be provided
4. Families, genetic specialists and primary care providers must communicate effectively
4. Care plans must be easily accessible by providers and families

Goals & Strategies

Goal 1: Facilitate collaboration within Region 4, with national partners and across regional collaboratives

- Solicit input and direction from stakeholders
- Establish/expand workgroups
- Facilitate ongoing communication
- Support parent participation
- Facilitate collaboration across regions

Goal 2: Develop & distribute follow-up protocols for population-based identification of children with heritable disorders

- Conclude efforts of Short Term NBS Workgroup
- Expand Follow-up Workgroup to include: EHDI, birth defects registry, early intervention
- Develop and disseminate follow-up protocols

Goal 3: Educate primary care providers, specialists & families about the importance of medical homes for children with heritable disorders

- Revise medical home materials to address heritable disorders
- Provide educational opportunities in each state
- Explore educating medical residents & nurses

Goal 4: Promote care coordination for children with heritable disorders

- Promote care plans for children with heritable disorders
- Implement the use of Emergency Information Forms (EIF)
- Revise EIF to facilitate electronic sharing of care plans

Outcomes

Goal 1

- Improve collaboration across stakeholder groups; among Region 4 states; with national partners & with other regions

Goal 2

- Improve follow-up practices for children with heritable disorders who are identified through: NBS, EHDI, birth defect registries, early intervention

Goal 3

- Increase # of parents and providers who understand how the medical home improves care and child outcomes
- Increase the number of parents advocating for their children to have a medical home
- Increase the # of children with heritable disorders being served by a medical home

Goal 4

- Increase access to care plans that are specific to heritable disorders
- Improve communication among families, specialists and primary care providers
- Improve quality of care for children with heritable disorders
- Increase access to emergency care plans for children with heritable disorders
- Increase the # of children with heritable disorders who have an accessible care plan

Assumptions

In order to successfully establish medical homes... the following conditions must exist (continued):

5. Reimbursement must be available for services integral to the medical home model, such as care coordination.

6. Parents and primary care providers must have easy access to information about specific disorders

6. Access to genetic expertise must be available, especially in underserved (rural) areas

7. Children with heritable disorders who are transitioning to adulthood will have better outcomes if:

- Families and providers are aware of the importance of a transition plan
- The transition plan is developed by the patient, the family and all care providers

Goals and Strategies

Goal 5: Address reimbursement issues that are barriers to quality care

- Identify barriers to reimbursement for care coordination; identify and implement strategies to resolve barriers
- Identify barriers to reimbursement for medical foods & formulas; identify and distribute successful strategies to resolve barriers

Revised Goal 6: Facilitate access to genetic information, resources, and disease management guidelines in the context of a medical home with a focus on underserved (rural) populations

- Promote the use of accurate disorder-specific resources
- Develop disorder-specific electronic grand rounds
- Promote links between genetic specialists and rural health service & communication systems
- Explore practice models to assist the limited number of genetic specialists in maximizing use of their time

Goal 7 (Previously Goal 8): Identify and promote effective models addressing transition to adult services for youth with heritable disorders

- Promote the use of individual transition plans
- Promote the use of strategies to develop and implement a systems approach to supporting transition
- Participate in the National Transition Workgroup
- Address regional needs identified through data analyzed by Healthy & Ready to Work

Outcomes

Goal 5

- Reduce barriers to reimbursement for care coordination
- Increase # of providers who understand how to overcome barriers to reimbursement for care coordination
- Increase knowledge of families and providers about strategies to overcome barriers to reimbursement for medical foods & formulas

Goal 6

- Improve access to genetic information within the context of the medical home
- Improve access to genetic expertise for underserved populations
- Maximize time of genetic specialists and genetic counselors so expertise is ultimately available to more families

Goal 7

- Improve access to transition plans & protocols for families & providers
- Increase skills of children & families to prepare for transition
- Increase the number of children transitioning to adult services who have a transition plan

Goal 1: Facilitate collaboration within Region 4, with national partners and across regional collaboratives						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Solicit input, advice, and direction from regional stakeholders on grant implementation	MPHI, Region 4 (R4) partners	Identify and invite Advisory Group representatives	Y1	List of Advisory Group Members	Improve collaboration <ul style="list-style-type: none"> • across stakeholder groups • among Region 4 states • with national partners • with other regions 	Percent of stakeholders satisfied with level of collaboration Number of <ul style="list-style-type: none"> • participants in Region 4 Genetics Collaborative • Region 4 stakeholder groups participating • parents actively involved • national partners involved • projects with other regions
	MPHI	Schedule and convene quarterly meetings	Y1-5	AG meeting notes		
	Workgroups	Identify barriers to grant implementation				
	MPHI	Present barriers to Advisory Group				
	Advisory Group (AG)	Recommend solutions to barriers				
		Review quarterly progress reports				
		Review and provide input on workgroup products				
	Provide input on overall grant direction					
Establish or expand the following Workgroups: <ul style="list-style-type: none"> • Medical Home Education • Care Coordination • Access to Genetic Expertise • MEMSCIS • Follow-up • Endocrine 	AG, R4 Partners	Identify and invite representatives from the following groups to participate: Family to Family; Genetic Alliance; AAP; AAFP; ACMG/NSGC; NCSL; Policy makers (e.g., legislative staff, State Medicaid directors); Health plans; Rural health organizations; Primary care providers; state genetics coordinators; Birth defects registries; EHDI; CSHCN; PHII; NCC	Y1	List of members		
	AG, R4 Partners	Identify workgroup chairs and co-chairs	Y1	List of workgroup chairs		
	MPHI	Plan and facilitate face-to-face workgroup meetings	Y1-5	Meeting notes		
Facilitate ongoing communication among Region 4 partners	MPHI	Conduct quarterly conference calls with the advisory group	Y1-5	AG conference call schedules, meeting notes, attendance records		
	MPHI	Conduct 10 conference calls per year with each workgroup	Y1-5			

Goal 1: Facilitate collaboration within Region 4, with national partners and across regional collaboratives						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
	MPHI	<i>Create email distribution lists for each workgroup/share with collaborative members</i>	Y1	Distribution lists posted to the website		
	MPHI, Website Developers	<i>Adapt the Region 4 website to align with the new structure and goals of the collaborative</i>	Y1	Website space devoted to each workgroup		
	MPHI, Website Developers	<i>Post workgroup meeting summaries, notes, updates and member lists, on the Region 4 website</i>	Y1-5	Contents of the website workgroup space		
	MPHI	<i>Convene a regional face to face meeting every 18 months</i>	Y2-3 Y5	Regional Meeting attendance records		
Support parent participation in collaborative activities	MPHI, R4 Partners	Establish partnerships with parent advocacy groups (e.g. Genetic Alliance, Family to Family Centers)	Y1	Letters of collaboration		
	Genetic Centers & Counselors, Parent Advocacy Groups	<i>Identify parent participants</i>	Y1	List of parent members		
	MPHI, R4 Partners	Identify parent co-chairs for the following workgroups: Education; Reimbursement; Care Coordination; Transition	Y1	List of workgroup chairs/co-chairs		
	MPHI	Hire parent coordinator to support parent members	Y1	Coordinator is hired		
	MPHI	Collaborate with Genetic Alliance to provide parent advocacy training⁺	Y1	Training records		
	Parent Coordinator	<i>Assist parents to prepare for workgroup meetings</i>	Y1- Y5	Meeting notes		
			<i>Work with NCC to share information with other regions</i>	Y1-5	Presentations at NCC meetings	

Goal 1: Facilitate collaboration within Region 4, with national partners and across regional collaboratives						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
	MPHI	Invite other regions to participate in Region 4 projects	Y1-5	List of other regions participating		
MPHI	Collaborate with other regions on national projects	Y1-5				

Goal 2: Develop and distribute best practice follow-up protocols/ practice models for population-based identification of children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Conclude efforts of the Short Term Workgroup (ST WG)	ST WG	Present products, practice models and recommendations to the Advisory Group	Y1	Advisory group meeting notes	Improve follow-up practices for children with heritable disorders who are identified through <ul style="list-style-type: none"> • Newborn Screening • Early Hearing Detection • Birth Defect Registries • Early Intervention 	Number of protocols identified, developed Number of best practice models identified Number of protocols/mod els implemented by Region 4 States
	ST WG	Disseminate Workgroup materials to Region 4 states and other regions	Y1	Distribution list		
	Genetic Specialists, Primary Care Providers	Review NBS follow-up information format provided by each Region 4 state	Y1	Meeting notes		
		Make recommendations for revisions to format increase usefulness to physicians	Y2	List of recommendations		
	ST WG	Revise state formats based as suggested	Y2	List of revisions		
Expand Follow-up WG (F WG) to include representatives of EHDI, Birth Defect Registries, Early Intervention Develop and disseminate follow-up protocols/ practice models	FWG, MPHI	Establish partnerships with EHDI, Birth Defects; CSHCN; Early Intervention	Y1-5	List of partners		
	FWG, MPHI, AG	Identify and recruit members to participate in the Follow up WG	Y1-5	WG members list		
	FWG	Identify protocols/for providing information at time of identification (positive screen, report, etc)	Y1-5	Written summary		
Expand Follow-up WG (F WG) to include representatives of EHDI, Birth Defect Registries, Early Intervention	FWG	Develop criteria for determining quality, cost and feasibility of replicating practice models	Y1-5	Written criteria		
	WG	Review practice models	Y1-5	Written summary		

Goal 2: Develop and distribute best practice follow-up protocols/ practice models for population-based identification of children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Develop and disseminate follow-up protocols/ practice models	MPHI	Poll states to determine which practice models they want to pilot	Y1-5	Practice models selected by states		
	TBD	Implement selected practice models in each state	Y1-5	Quarterly reports		
	Evaluator	Evaluate implementation	Y2-5	Evaluation report		
	FWG	Adapt, refine practice models/ products based on evaluation findings	Y3-5	Revised products, practice models		
	R4 Partners	Disseminate protocols and models	Y1-5	Products posted, list of dissemination activities		

Goal 3: Educate primary care providers, specialists and families about the importance of providing a medical home for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Revise medical home educational materials to so they are specific to the needs of children with heritable disorders	Medical Home Education Workgroup, (EWG), MPHI	Identify existing state/national educational initiatives	Y1	List of training initiatives	Increase # of parents and providers who understand how the medical home improves care and child outcomes	Percent of families and providers who participate in presentations, online courses, consultations (etc.) who indicate their understanding has increased
		Develop criteria for determining quality, cost and feasibility of replicating initiatives	Y1	Written criteria		
		Review existing initiatives/materials by selected criteria	Y1	Written reviews		
		Summarize initiatives/materials based on criteria	Y1	Written summary	Increase # of parents advocating for their children to have a medical home	Extent Region 4 parents engage in advocating for medical homes
		Select initiatives/materials to be promoted by Region 4	Y1	List of selected initiatives/material		
		Select the most effective dissemination method for each stakeholder group (on-line course, face-to-face training, individual consultation, etc.)	Y1	List of dissemination methods	Increase the # of children with heritable disorders being served by a	
		Revise existing educational materials to ensure they are	Y2	Revised materials		

Goal 3: Educate primary care providers, specialists and families about the importance of providing a medical home for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
		applicable to Region 4 states and heritable disorders			medical home	
		Distribute revised materials to Region 4 partners, other regions		Distribution list		
	EWG, State Consultants	Review and finalize presentation and display materials	Y2	Finalized materials		
	MPHI	Work with partners to identify educational opportunities	Y2	List of educational opportunities		
	MPHI	Schedule presentations with pediatricians, specialists, families	Y2	Schedule of presentations,		
	State Consultants	Provide educational opportunities in each Region 4 state	Y2-5	List of participants		
	Explore educating medical residents and nursing students about the medical home model	EWG	Review information on current initiatives to educate medical residents and nursing students	Y3		
Develop criteria to rate the quality, cost and feasibility of replicating initiatives			Y3	Written criteria		
Review current initiatives using criteria and effectiveness data			Y3-4	Meeting notes		
Prepare summary of findings			Y3-5	Summary report		
Share strategies to educate medical residents and nursing students with Region 4 partners			Y3-5	List of how materials were shared		

Goal 4: Promote care coordination for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Promote the use of care plans specific to the needs of children with heritable disorders	Care Coordination Workgroup (CCWG), MPHI	Collect examples of care plans and protocols	Y1	List of existing tools/ protocols	Increase access to care plans that are specific to heritable disorders	Estimated number of families, specialists and primary care providers accessing care plans
		Develop criteria with which to review care plans and protocols	Y1	Written criteria		
		Review care plans and protocols using established criteria	Y1	Written review		

Goal 4: Promote care coordination for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
		Select care plans and protocols to adapt based on criteria	Y1	List of selected tools and protocols		
	CCWG, MPHI	Define the elements of care plans and care coordination protocols unique to children with heritable disorders	Y1	List of unique elements		
		Integrate the elements of a care plan unique to children with heritable disorders	Y1	Adapted tools and protocols		
	R4 Partners	Disseminate care plans and protocols and recommendations for use to genetic specialists, primary care providers and families of children with heritable disorders	Y2	List of presentations and website links		
Create Learning Consortia to resolve barriers to effective communication among families, specialists and primary care providers	CCWG	Discuss barriers to effective care coordination and develop solutions	Y2-3	Summary of barriers and solutions	Improve communication among families, specialists, and primary care providers Improve quality of care for children with heritable disorders	Percent of Learning Consortium members who indicate improved communication Percent of children with heritable disorders served by specialists and primary care providers that have improved health outcomes and quality of life (pre-post test)
	CCWG, GEWG, MHWG	Explore partnering with established learning consortia to serve as a resource for exploring newborn screening and access to genetic services in the context of the learning consortia				
Implement the use of web-based Emergency Medical Information Forms (EIF) specific to the needs of children with heritable	Midwest Emergency Medical Services for Children Information System	Obtain participation of all 17 metabolic centers	Y1	List of centers participating	Increase access to emergency care plans for children with heritable disorders	Number of metabolic centers participating Number of children with web-based emergency information forms

Goal 4: Promote care coordination for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
disorders by expanding the implementation of the MEMSCIS system in Region 4	(MEMSCIS) Coordinator Metabolic Centers Metabolic Centers	<i>Distribute enrollment materials</i>	Y1-5	Distribution list	Increase access to emergency care plans for children with heritable disorders	Number of metabolic centers participating
		Identify staff from centers to enter data		Contact list		
		<i>Provide technical assistance (TA) to participants on how to use EIF</i>	Y1-5	Log of TA requested/ provided		
		Provide template language for IRB approval process within participating institutions	Y1-2	List of selected tools & protocols		
		Obtain IRB approval	Y1-2, ongoing	IRB applications approved		
		Enroll families • Provide information about EIF • Obtain informed consent Enter new enrollee data	Y1-5	EIF card provided to families		
	Metabolic Centers, ER Staff, PCP Staff, Families	• Update EIF with health status changes	ongoing	Updated EIFs	Increase the # of children with heritable disorders who have an accessible care plan	Number of care plans accessible through Region 4 projects
	Metabolic Centers, ER Staff, PCP Staff, families, Coordinator	Distribute information about EIF system to hospitals, PCPs, other potential users	Y1-5	Distribution lists		
	Evaluator	Evaluate and make recommendations for modifications based on results	Y3	Evaluation report		
	MEMSCIS staff, Priority 2 WG, AG	Identify other heritable disorders for participation in MEMSCIS and recruit participants	Y4-5	List of disorders		
	MEMSCIS Coordinator	Research funding strategies to continue support	Y4-5	List of possible funding sources/strategies		
	MEMSCIS Workgroup	Establish a MEMSCIS National Advisory Board				
	Priority 2	Cross reference participant data	Y2-5	Data on		

Goal 4: Promote care coordination for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
	Coordinator, MEMSCIS Coordinator, data base developers	between MEMSCIS and IBEM-IS		emergency encounters correlated with treatment, medical home		
Facilitate interoperability between the web-based server used in the IBEM-IS (Priority 2) Project and the web-based server used in the MEMSCIS project	CCWG	Select elements of care plans unique to children with heritable disorders to be integrated with the EIF	Y3	List of data elements		
Revise EIF to facilitate electronic sharing of care plans among primary care, specialists, emergency care providers, families	MEMSCIS staff	Work with software contractor to add data elements to EIF	Y3	Software revisions completed	Increase the # of children with heritable disorders who have an accessible care plan	Number of care plans accessible through Region 4 projects
	MEMSCIS, Priority 2 staff	Educate metabolic centers about addition of care plan elements to EIF system	Y3	Distribution list		
	Metabolic Centers	Enter care plan elements to individual case records	Y4	Written review		
	Specialists, PCP, ER, family	Use electronic care plans to coordinate care	Y4-5			

Goal 5: Address reimbursement issues that create barriers to quality care for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Identify barriers to reimbursement of services integral to the medical home (e.g. care coordination)	National Conference of State Legislators (NCSL)	Identify and review national policies related to reimbursement issues	Y3	List of policies impacting reimbursement	Increase number of policy makers who are aware of barriers to reimbursement for care coordination	List of articles published by NCSL
	NCSL, Reimbursement WG, (RWG) MPHI	Gather input from stakeholders about real and perceived barriers	Y3	List of barriers		Reduce barriers to reimbursement for care coordination
	RWG, MPHI	Review literature on barriers & solutions to reimbursement issues	Y3	Written literature review	Increase number of providers who understand how to overcome barriers to being reimbursed for care coordination	List of barriers overcome
	MPHI	Summarize information from all sources	Y3	Written summary		Number of families and providers educated
	NCSL	Prepare articles for publication	Y3-5	Written articles		Percent of providers participating in educational opportunities that indicate they have a
	RWG	Prioritize reimbursement issues to be addressed	Y1	List of priorities		
Identify and implement strategies to resolve barriers to reimbursement for care coordination	RWG, NCSL, Advisory Group	Identify successful strategies and gather effectiveness data (e.g. coding and policy changes)	Y2	List of strategies		better understanding of how to overcome barriers to reimbursement
	RWG	Summarize strategies including feasibility and cost of implementation	Y2	Written summary		
	MPHI	Poll states to determine which strategies they want to implement	Y2	List of states and selected strategies		
	RWG	Pilot strategies in selected states	Y2-5	List of strategies implemented		
	Evaluator	Evaluate strategies based on outcome data and modify as indicated	Y3-5	Evaluation results		
	RWG	Expand strategies to additional Region 4 states	Y3-5	List of states implementing strategies		
Identify strategies to resolve barriers to reimbursement for medical foods and formulas	NCSL	Identify and review state legislation and policies around reimbursement for foods and formulas	Y4	List of policies impacting reimbursement	Increase knowledge of families and	Estimated number of families and

Goal 5: Address reimbursement issues that create barriers to quality care for children with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
and distribute to Region 4 partners	RWG	Review literature on barriers and solutions to reimbursement issues	Y4	List of barriers	providers about strategies to overcome barriers to reimbursement for medical foods and formulas	providers educated about strategies to overcome barriers to reimbursement for medical foods and formulas
	RWG	Summarize information from all sources	Y4	Written literature review		
	RWG	Prioritize reimbursement issues to be addressed	Y4	Written summary		
	RWG	Identify successful strategies and gather effectiveness data	Y5	List of model strategies		
	RWG	Summarize strategies including feasibility and cost of implementation	Y5	Written summary		
	MPHI	Share summary with R4 partners	Y5	List of ways summary was shared		

Revised Goal 6: Facilitate access to genetic information, resources, and disease management guidelines in the context of a medical home with a focus on underserved (rural) populations							
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator	
	Who	What	When				
Promote the use of accurate and up-to-date disorder specific resources for primary care providers and families	MPHI, Information Workgroup (GEWG) FWG	Identify existing national and regional resources/materials that are evidence or consensus-based	Y2-3	List of resources	Improve access to genetic information within the context of a medical home	Number of types of materials available	
		Review CC & FS WG “Quality Assessment criteria for Families”	Y2-3	Conference call meeting notes			# of ways in which materials are available
		Develop criteria for determining quality of existing resources/materials by diagnostic category	Y2-3	Written criteria			
	GEWG; FWG	Review existing materials by selected criteria	Y2-3	Written review summary		Percent of Region 4 partners that	<ul style="list-style-type: none"> • indicate usefulness of information • ease of access
		Identify quality materials for packaging and marketing	Y2-3	List of quality materials			
		Adapt quality materials to include new disorders as additional ACT sheets are released	Y2-5	Materials are up to date			
		Review written summary of the effectiveness of delivery methods prepared by the Education WG	Y2	Conference call notes			

Revised Goal 6: Facilitate access to genetic information, resources, and disease management guidelines in the context of a medical home with a focus on underserved (rural) populations						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
		Collaborate with Follow-up WG to make materials available upon identification i.e. with positive screen, birth defect report	Y2	Meeting notes, Written plan		
		Develop plan to disseminate information and materials	Y2	Written plan		
	GEWG and Region 4 partners	Package and disseminate quality materials throughout Region 4 states	Y2-5	Packaged materials, postings		
	FWG	Implement plans to incorporate material dissemination into follow up activities	Y2-5	Summary of dissemination activities		
Develop disorder specific electronic grand rounds/web casts to address gaps in information (targeted at primary care providers)	GEWG MPHI	Gather input from stakeholders about information needs and gaps (focus groups, web-based surveys, conference surveys, etc.)	Y2	Written summary		
	GEWG	Identify gaps in quality resources	Y2	Written summary		
		Select topics based on group research of information gaps	Y2	List of topics		
		Identify genetic experts to develop content outline	Y3-5	List of experts		
	WG & Content experts	Develop content outline	Y3-5	Outline		
	GEWG	Identify experts to create and deliver presentations	Y3-5	Experts identified		
	MPHI	Develop subcontracts with experts	Y3-5	Subcontract with specialist		
	GEWG	Explore web cast production methods and vendors with a focus on web casts aimed at rural providers	Y2-5	Summary of methods and vendors		
	GEWG	Select vendor	Y3-5	Vendor identified		

Revised Goal 6: Facilitate access to genetic information, resources, and disease management guidelines in the context of a medical home with a focus on underserved (rural) populations						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
	MPHI	Develop vendor subcontract	Y3-5	Vendor subcontract		
Partner with SERGG to adapt “Ask the Geneticist” website feature for use in Region 4	GEWG; MPHI	Partner with South East Regional Genetics Group (SERGG)	Y1	Written agreement		
	GEWG	Add link from Region 4 website	Y1	Activated link		
	GEWG	Actively promote SERGG website as a resource	Y1-5	List of promotional activities		
Promote links between genetic specialists, existing rural initiatives and telemedicine networks	MPHI Expertise Workgroup (GEWG); Rural Health Initiatives	Identify rural health initiatives in Region 4 and establish partnerships	Y2	List of rural health partners	Improve access to genetic expertise for rural populations in Region 4	Percent of rural health partners that indicate access to genetic expertise has been improved
		Identify existing rural health service delivery and communication systems including telemedicine networks	Y2	Summary of existing systems		
	GEWG	Work with existing telemedicine networks to develop opportunities for geneticists to provide expertise to rural providers	Y3-5	List of telemedicine network partnerships		
	GEWG	Create protocols for providing genetic expertise using web-based resources	Y3	Written protocols		
	GEWG, MPHI	Distribute protocols to rural health partners and genetic specialists	Y3-5	Distribution list		
	Fleisher	Provide expertise to primary care providers and genetic specialists on the legal aspects of telemedicine	Y3-5	Summary of expertise provided		
Explore practice models to assist the limited number of genetic specialists in maximizing the effective use of their time	MPHI GEWG, Genetic Specialists	Identify practice models for genetic specialist service delivery	Y3	Summary	Maximize time of genetic specialists and genetic counselors	Specialists’ and counselors’ perceptions of time saved (interview)
		Develop criteria for reviewing models for effectiveness, cost, feasibility	Y3	List of criteria		

Revised Goal 6: Facilitate access to genetic information, resources, and disease management guidelines in the context of a medical home with a focus on underserved (rural) populations						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
		Summarize information on service delivery models	Y3	Written summary		Primary care providers' perceptions of access to genetic expertise Families' perceptions of quality of care (survey)
	MPHI GEWG, Genetic Specialists	Disseminate information on practice models to R4 partners and other regions	Y3-5	List of how information was disseminated		
		Select one model for pilot project	Y3	Description of model		
		Identify site to pilot practice model	Y3	Name of site		
	TBD	Implement pilot project	Y4	List of providers participating		
	Evaluator	Evaluate project and distribute findings	Y5	Written evaluation		

Goal 7 (Previously Goal 8): Identify and promote effective models addressing transition to adult services for youth with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
Promote the use of individual transition plans specific to the needs of children with heritable disorders	Transition WG (TWG), MPHI	Collect examples of transition plans and protocols	Y3	List of existing tools/protocols	Improve access to transition plans and protocols for families and providers Increase skills of children and families to prepare for transition	Percent of R4 partners who indicate transition plans and protocols are • useful • easy to access
		Develop criteria with which to review transition plans/protocols	Y3	Written criteria		
	TWG, MPHI	Review transition plans and protocols using established criteria	Y3	Written review		
	TWG, MPHI	Select transition plans and protocols for adaptation (state specific and disorder specific)	Y3	List of selected tools and protocols		
	TWG, MPHI	Define elements of individual transition plans unique to children with heritable disorders	Y4	List of unique elements		
		Integrate the elements of an individual transition plan into transition plan templates	Y4	Adapted tools and protocols		

Goal 7 (Previously Goal 8): Identify and promote effective models addressing transition to adult services for youth with heritable disorders						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
		Disseminate transition protocols & recommendations for use to families, CSHCS, primary care, genetic and	Y4	List of presentations and website links	Increase the number of children transitioning to adult services who have a transition plan	Number of children and parents participating in activities to prepare for transition
	Nisonger Center	other specialty clinic providers Assist children with heritable disorders and their families to prepare for transition	Y3-5	Description of activities; list of participants		
Participate in the national transition workgroup	Co-chairs R4 Coord.	<i>Participate in monthly phone calls</i>	Y3-5	Meeting notes		
	TWG & R4 staff	<i>Assist in transition data collection efforts in Region 4 states</i>	Y3-4	Data submitted		
Address regional needs identified through data gathered by the national workgroup	TWG, MPHI	Review Region 4 data collected by Healthy and Ready to Work	When data are available	Meeting notes	Percent of children and families participating in educational activities that indicate they are better prepared for transition	
		Summarize the Region 4 needs identified through data collection		Written summary		
		Prioritize Region 4 needs		List of priorities		
		Develop a plan to address Region 4 priority needs		Action plan		
		Implement the plan to address Region 4 priority needs		Action plan updated		
Identify strategies to develop a systems approach to promoting transition and distribute to Region 4 partners	TWG, MPHI	Identify state programs (e.g. CSHCN and Genetics) that promote transitions & state compile activities	Y3-4	List of programs, activities	Increase the number of state programs promoting transition	Number of state programs implementing activities to promote transition
		Develop criteria with which to review strategies	Y3	Review criteria		
		Review strategies using criteria	Y3-4	Summary		
		Disseminate selected strategies and recommendations for implementation to state systems to promote transition	Y3-5	Written summary, web posting		