HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

CHILD'S INFORMATION		
Child's Full Name:		
Child Adopted, Foster, or Biological:		
Street Address:		
City:	State:	ZIP Code:
Child's Blog, Website, or Facebook Page:		
Photo Release Form (circle one): SIGNED DENIED		
Date of Birth:	Gestational Age at Birth:	
Place of Birth:		
Mailing Address of Facility:		
City:	State:	ZIP Code:
Diagnosis Details; to include pregnancy, birth, and details given upon diagnosis:		

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Additional Diagnoses Given; include as many details as possible (dates, descriptions, etc.):	
Date of Death:	Place of Death:

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Cause of Death:

APPROVED POINTS-OF-CONTACT

Your Name:	Relationship to Child:

_____(initial) I certify that I am the primary point of contact for the child named above and serve as the child's primary care provider as biological/adopted parent or custodial caregiver. If I am not the primary care provider, I certify that I have been given permission to complete this application on that person's behalf for the reason listed here:

Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:
Name:	Relationship to Child:	

_______ (initial) I certify that this individual is an active part of child's care (will notify of any change in status). This will approve their addition to the family-to-family resource network on Facebook – as well as approve correspondence with Global Hydranencephaly Foundation & its volunteers for awareness, advocacy & informational purposes.		
Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:
Name:	Relationship to Child:	
_______ (initial) I certify that this individual is an active part of child's care (will notify of any change in status). This will approve their addition to the family-to-family resource network on Facebook – as well as approve correspondence with Global Hydranencephaly Foundation & its volunteers for awareness, advocacy & informational purposes.		
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Mailing Address:		
City:	State:	ZIP Code:
Name:	Relationship to Child:	
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Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:
Name:	Relationship to Child:	

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DATE COMPLETED: ______________________________________

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Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:
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Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:

UNIQUE FAMILY CIRCUMSTANCES

If there are any family circumstances that you would like to make us aware of, please share those here (individuals who may not receive information from GHF, The desire for a greater level of confidentiality, personal concerns of any nature, etc.)

HEALTH HISTORY

Name of Primary Care Facility:		
Primary Physician/Pediatrician:		
Phone:	E-mail:	
Mailing Address:		
City:	State:	ZIP Code:

SPECIALISTS SEEN

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		
Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		
Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		
Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		
Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Specialist Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Specialist Details (length of time seen, symptoms seen for, etc.):		

THERAPY SERVICES RECEIVED

Therapy Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Treatment Details (length of time seen, symptoms seen for, etc.):		
Therapy Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Treatment Details (length of time seen, symptoms seen for, etc.):		
Therapy Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Treatment Details (length of time seen, symptoms seen for, etc.):		
Therapy Type:		
Full Name:		
Phone:	Email:	
Mailing Address:		
City:	State:	ZIP Code:
Treatment Details (length of time seen, symptoms seen for, etc.):		

ALTERNATIVE TREATMENT OPTIONS EXPLORED

Treatment:	Duration:

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Treatment Details:	
Treatment:	Duration:
Treatment Details:	
Treatment:	Duration:
Treatment Details:	

PHARMACEUTICAL INTERVENTIONS	
Prescription:	Dosage:
Details:	
Prescription:	Dosage:
Details:	
Prescription:	Dosage:

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Details:	
Prescription:	Dosage:
Details:	
Prescription:	Dosage:
Details:	

SPECIFIC NEEDS

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

GHF is a family-centered nonprofit entity providing individualized support to families facing diagnosis of hydranencephaly for tehir child. If there are any specific needs that are required to help you in providing your family the best quality of life on the journey with a hydran child, please share those here:

SUPPORT GROUP ACTIVITY, VOLUNTEER OPPORTUNITIES & NEWSLETTER

Family-to-Family Resource Network on Facebook:

YES NO, PLEASE ADD ME NO, NOT INTERESTED

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

Hydran-Angel Family Group on Facebook:

YES NO, NOT NECESSARY NO, PLEASE ADD ME

NO, NOT INTERESTED

Please subscribe me to the Bee's Buzz, monthly e-newsletter:

YES NO, Already Subscribed NO, NOT INTERESTED

Email address to subscribe:

I am interested in being a regional/state contact individual. This opportunity will involve a small amount of online training from Global Hydranencephaly Foundation and make my email/phone number available to families via both web at www.hydranencephalyfoundation.org and print materials. I agree to be available for contact by families in my area to answer questions or provide support that is specific to our area (circle one):

YES NO

Best Email for This Purpose:

Best Phone Number for This Purpose:

(circle preference): CALL TEXT

BRAIN SCAN IMAGES

HYDRANENCEPHALY MEDICAL HISTORY & FAMILY INFORMATION SURVEY

DATE COMPLETED: _____

IF YOU ARE ABLE TO INCLUDE BRAIN SCAN IMAGES IN ANY FORMAT, IT WOULD BE EXTREMELY BENEFICIAL TO OUR MISSION. YOU MAY SEND THEM BY SCANNING AND EMAILING THEM WITH THIS APPLICATION OR BY USPS ON DISC OR IN PRINT COPIES.

HAVE YOU INCLUDED DIAGNOSTIC SCAN IMAGES WITH THIS SURVEY:

YES **NO**

SIGNATURE

By signing below, I confirm that I have read the attached information regarding the use of information obtained from this survey. I hereby authorize the inclusion of this information in to the database for Brayden Alexander Global Foundation for Hydranencephaly, Inc. I understand that my information will be shared anonymously for purposes of awareness and advocacy.

Signature of applicant:	Date:

Feel free to include additional pages as necessary for fulfilling the requests of this application.

Pages Attached: _____