CCSS Biorepository

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Saliva Collection

In December 2007, collection of a saliva sample using the Genotek Oragene-DNA Self-Collection Kit was initiated. Oragene-DNA yields high-quality, high-quantity (@ 110ug) DNA from a small saliva sample. Oragene-DNA is optimized to preserve and stabilize saliva samples for long term storage at room temperature without DNA degradation. DNA from Oragene-DNA is equivalent to DNA from blood and has been successfully used for PCR and genotyping in genome-wide Association studies.

Buccal Cell Collection

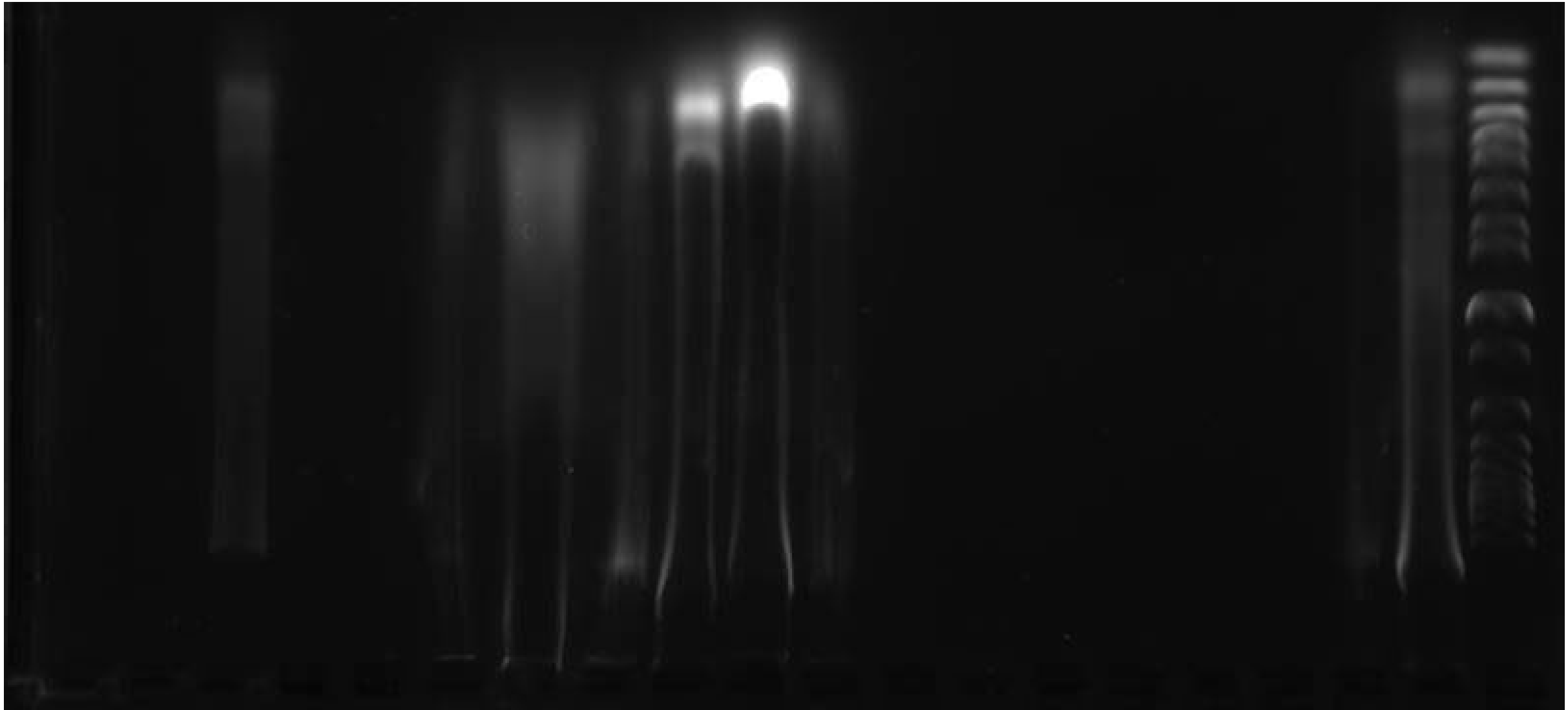
Collection of buccal cell genomic DNA occurred during May 1999 and June 2006 using a mouthwash kit.

Eligible individuals had completed a baseline questionnaire after enrollment into the cohort, had a known current address, were alive at the date of the request for a buccal cell sample, and had been enrolled in CCSS at a site with institutional review board approval for collection and storage of buccal cell DNA.

Participants were mailed a specimen collection kit that included a cover letter describing the study, consent form, instruction sheet, 45 ml. bottle of mouthwash, specimen collection container, return mail labels, and postage. Subjects were instructed to rinse their mouths with the mouthwash and return the used mouthwash to the Molecular Genetic Laboratory in Cincinnati, Ohio, in the sterile container.

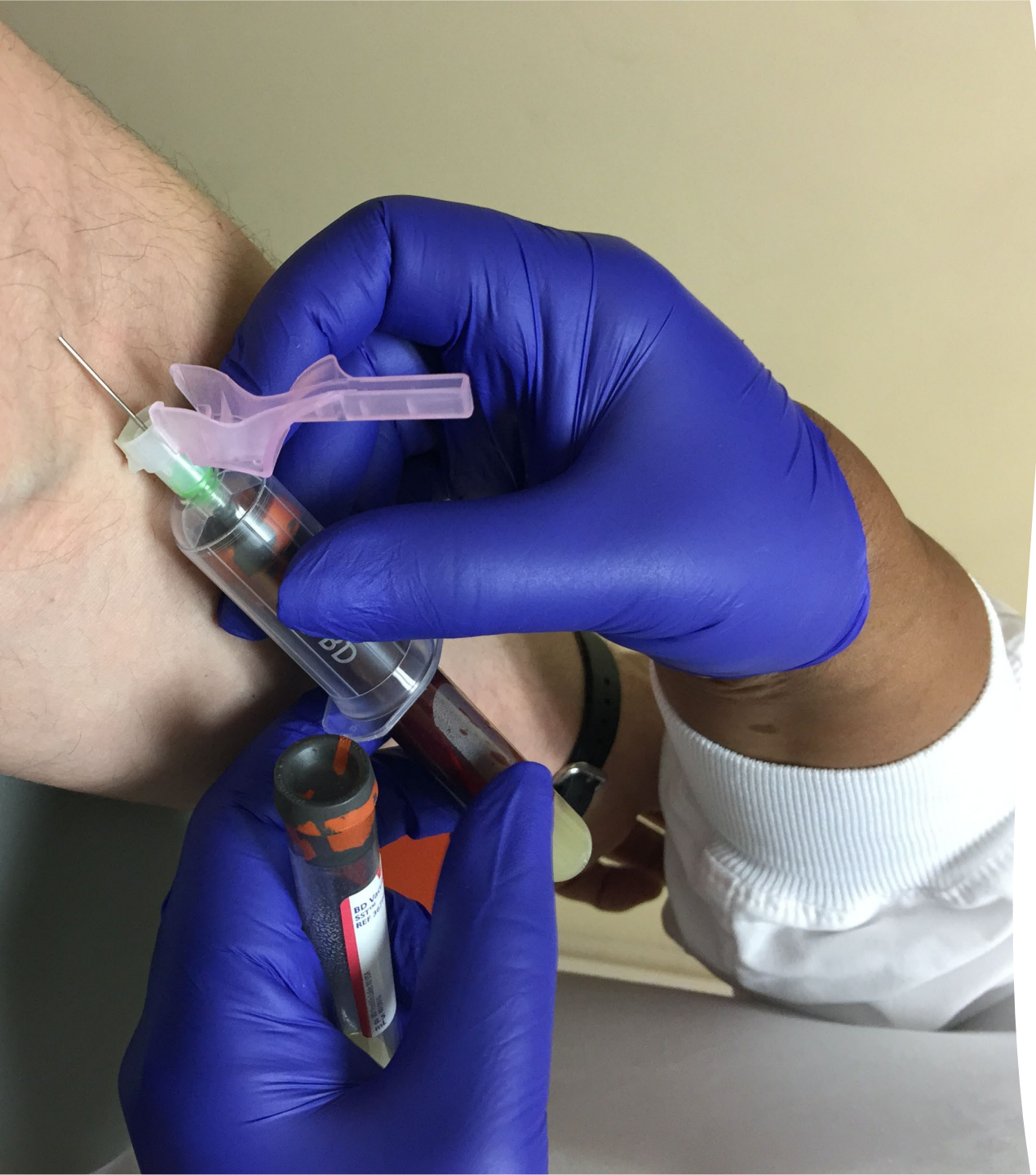
Getting Old Together

DNA Getting Old!



Complete Collection

Typecode	Diagnosis		Buccal + Oragene	Buccal + Blood	Oragene + Blood	Buccal + Oragene + Blood	At Least One of the three samples
			Total Number Cases sample Collected	Total Number Cases sample Collected	Total Number Cases sample Collected	Total Number Cases sample Collected	Total Number Cases sample Collected
1	Leukemia		677	86	648	491	4177
		Acute lymphoblastic leukemia	615	76	530	445	3568
		Acute myeloid leukemia	51	9	89	31	470
		Other leukemia	11	1	29	15	139
2	CNS		285	18	344	113	2103
		Astrocytomas	171	10	172	66	1226
		Medulloblastoma, PNET	68	7	121	23	533
		Other CNS tumors	46	1	51	24	344
3	Hodgkins Lymphoma	Hodgkins disease	235	37	322	252	1666
4	Non-HD Lymphoma	Non-Hodgkins lymphoma	150	12	154	114	1065
5	Kidney	Kidney tumors	232	17	138	117	1219
6	Neuroblastoma	Neuroblastoma	170	9	106	73	947
7	Soft tissue sarcoma	Soft tissue sarcoma	173	19	117	127	907
8	Bone		136	14	227	160	1039
		Ewings sarcoma	54	2	89	44	350
		Osteosarcoma	71	12	128	113	633
		Other bone tumors	11	0	10	3	56
9	Sibling Controls		592	0	0	0	2232
	TOTALS		2650	212	2056	1447	15355



Blood Samples: specific clinical phenotypes and specific studies

- Subsequent malignant neoplasms
- Interventional or observational studies with direct patient contact and necessary funding

Blood								Lymphocytes		EBV	
Total Number of Cases with Sample	Number with Volume >5ml	Number with Volume >50ml	Total Number of Cases Plasma Collected	Total Number of Cases Monocytes Collected	Total Number of Cases Neutrophils Collected	Total Number of Cases Whole Blood Collected	Total Number of Cases Lymphocytes for Culture Collected	Total Number of Cases with Sample	Total Number of colletions	Total Number of Cases with Sample	Total Number of colletions
1455	1445	639	1423	872	1437	573	1424	1435	1508	121	128
1237	1229	590	1211	778	1221	446	1208	1218	1284	109	116
161	160	36	158	64	160	97	160	161	165	7	7
57	56	13	54	30	56	30	56	56	59	5	5
563	558	108	553	220	557	335	553	551	565	55	57
294	291	53	290	111	294	174	292	291	293	28	29
177	175	38	175	73	175	107	174	172	182	13	13
92	92	17	88	36	88	54	87	88	90	14	15
707	704	219	682	430	692	256	686	696	751	125	132
346	344	109	343	161	343	185	342	339	358	27	27
317	317	89	317	135	317	186	317	314	328	23	25
220	219	59	215	98	218	119	217	217	226	23	23
301	301	59	297	123	301	169	298	299	310	44	44
475	473	102	467	192	467	285	466	468	487	56	57
152	151	32	148	63	147	90	147	151	156	19	19
305	304	69	301	124	302	184	301	300	314	34	35
18	18	1	18	5	18	11	18	17	17	3	3
1	1	0	1	0	1	1	1	0	0	0	0
4385	4362	1384	4298	2231	4333	2109	4304	4319	4533	474	493

Whole Genome Data

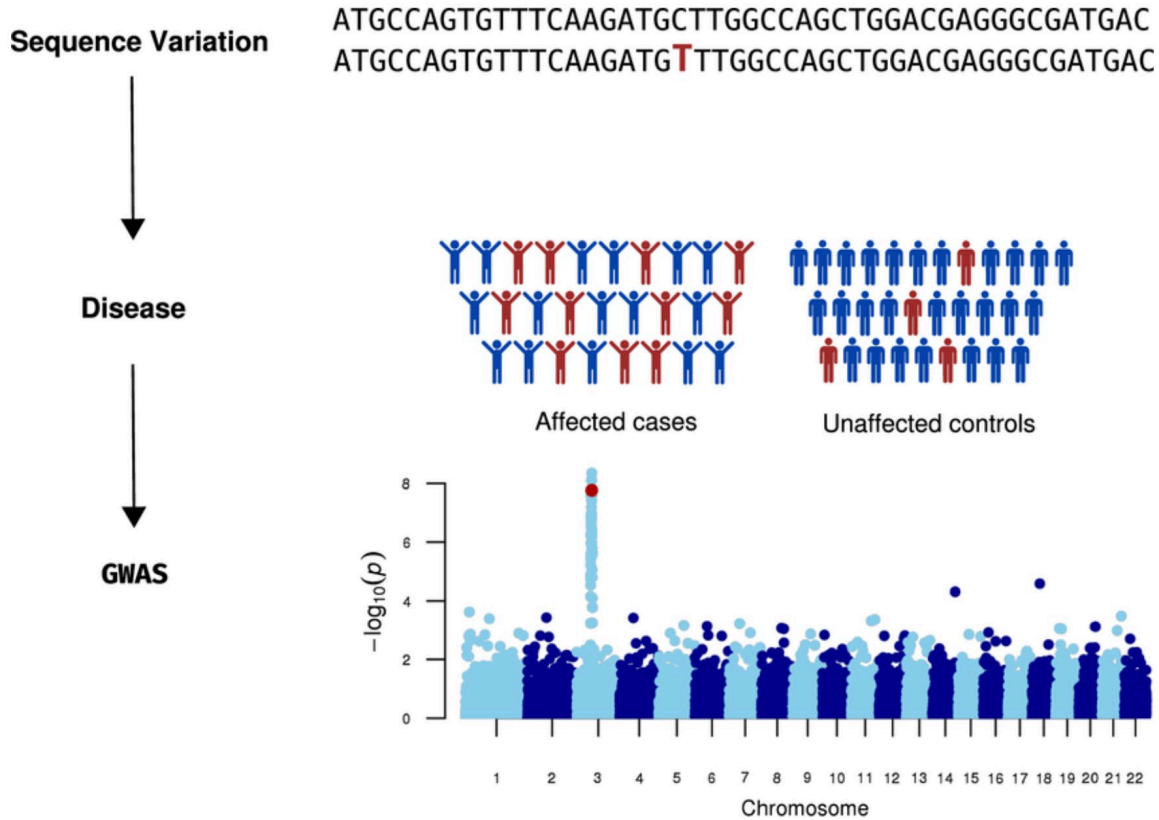
BAM files and phenotype data available to all investigators through completion of a Data Access Procedures process in the St. Jude Cloud.

Public Access Whole Genome Data Tables

The table below provides characteristics for genome sequenced CCSS participants.

Characteristic	CCSS Participants with Whole Exome Data (N=2641)	
	N	%
Sex		
Male	1240	47.5
Female	1401	52.5
Ancestry (based on genotype)		
European	2114	78.8
Non-European	527	21.2

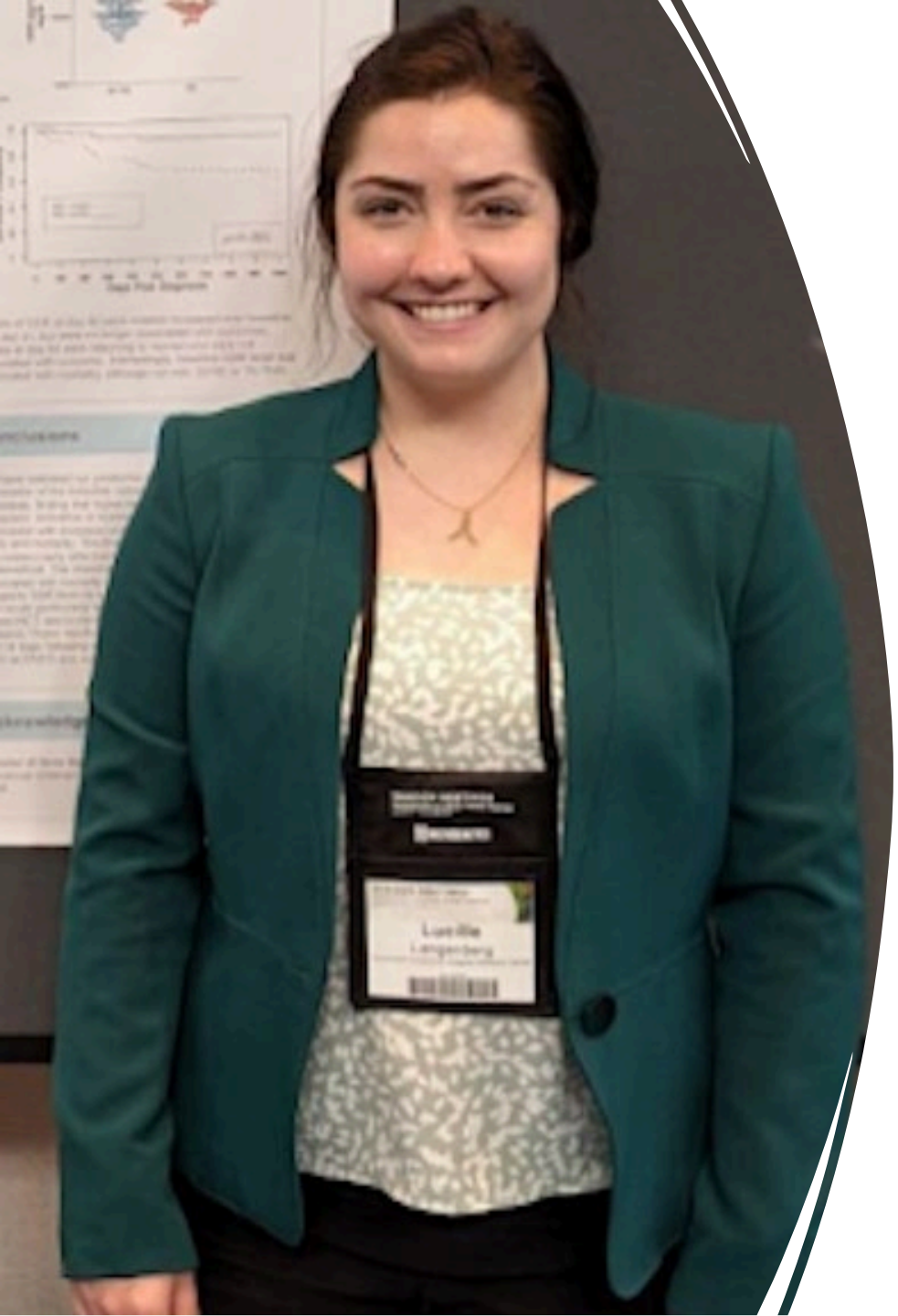
GWAS Data Resource



The Childhood Cancer Survivor Study genome-wide association study (GWAS) dataset is available to investigate the role of genetic susceptibility in the development of non-malignant treatment-related outcomes (in addition to subsequent malignancies) in cancer survivors. This process is open to investigators through collaboration with CCSS and National Cancer Institute investigators in the use of existing GWAS data and corresponding outcomes-related data to address innovative research questions relating to potential genetic contributions to risk for treatment-related outcomes through submission of an Application of Intent. The links below will guide you in submitting a proposal.

Biorepository Summary

- Samples are a gracious gift from our participants and are an invaluable resource and can strengthen almost any grant application
- CCSS will be very happy if all the samples get used!
- Data are forever- resources like the GWAS and genome sequencing dataset are available, already paid for and can also greatly enhance a project



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