

## GenTAC Alliance Registry Summary Table

June 2022

	Institution															
	University of Michigan	Centro Cardiologico Monzino	Texas Children's Hospital	Aortic Institute at Yale New Haven	Stanford Hospital	St. Michael's Hospital	Duke University	Boston University	NHLBI	Ehlers-Danlos Society	University of Texas HSC Houston	University of Texas HSC Houston	University of Texas HSC Houston	University of Washington	University of Kentucky	Pediatric Heart Network
<b>Date Last Updated</b>	9/20/2021	7/2021	10/24/2021	7/2021	7/2021	7/2021	7/2021	3/18/2022	10/28/2021	9/29/2021	12/13/2021	12/13/2021	12/13/2021	3/30/2022	10/5/2021	12/9/2021
<b>Registry Name</b> <i>Add hyperlink.</i>	<a href="#">IRAD</a>		<a href="#">CLARITY</a>					<a href="#">BAVcon</a>	<a href="#">GenTAC</a>	<a href="#">Ehlers-Danlos Society Registry</a>	<a href="#">Montalcino Aortic Consortium</a>	<a href="#">Turner Syndrome Society of the United States Research Registry</a>	UTHealth Bicuspid Aortic Valve Research Registry	VEDS Collaborative		<a href="#">Atenolol vs. Losartan Trial</a>
<b>Principal Investigator</b> <i>Add name and hyperlink email.</i>	<a href="#">Kim Eagle</a>	<a href="#">Andrea Ballotta</a>	<a href="#">Shaine Morris</a>	<a href="#">John A. Elefteriades</a>		<a href="#">Mark Peterson</a>	<a href="#">G. Chad Hughes</a>	<a href="#">Simon Body</a>	<a href="#">BioLINCC</a>	<a href="#">Lara Bloom</a>	<a href="#">Dianna Milewicz</a>	<a href="#">Siddharth Prakash</a>	<a href="#">Siddharth Prakash</a>	<a href="#">Sherene Shalhub</a>	<a href="#">Mary B. Sheppard</a>	
<b>Coordinator/Primary Contact</b> <i>Add name and hyperlink email.</i>	<a href="#">Elise Woznicki</a>		<a href="#">Nadia Espahbodi</a> <a href="#">Aisha Matthews</a>		<a href="#">Mitchel Pariani</a>		<a href="#">Melissa Burkett</a>			<a href="#">Scott Stoll</a> <a href="#">Sravva Konakananchi</a>	<a href="#">Maura Boerio</a>	<a href="#">Cindy Scurlock</a>	<a href="#">Lance Babcock</a>			
<b>Other Investigators</b> <i>Include names only.</i>	Investigators from 53 active centers.	Camilla L'Acqua	Justin Weigand, Taylor Beecroft, Josephine Martin, Ben Jacob, Emily Soludczyk		David Liang, Craig Miller, Joshua Spin, Mirela Tuzovic	Kim Connelly, Geraldine Ong		Simon Body, Andrea Ballotta, Malenka M Bissell, Yohan Bossé, Eduardo Bossone, María Brion, Rodolfo Citro, Carlo de Vincentiis, Alessandro Della Corte, Ronen Durst, Eric Eisselbacher, Arturo Evangelista, Dan Gilon, Betti Giusti, Gordon Huggins, Giuseppe Limongelli, Patrick Mathieu, Hector Michelena, Dianna Milewicz, Jochen Muehlschlegel, Stefano Nistri, Francesca Pluchinotta, Siddharth Prakash, Thor Sundt, Sébastien Thériault		Clair A. Francomano, Woodrow Gandy	Siddharth Prakash, Alana Cecchi	Michael Silberbach	Dianna Milewicz	Peter Byers		
<b>Data Forms / Dictionary Links</b> <i>Include hyperlinks or send as attachment(s).</i>									<a href="https://biolincc.nhlbi.nih.gov/studies/genac/">https://biolincc.nhlbi.nih.gov/studies/genac/</a>							<a href="https://www.pediatricheartnetwork.org/studies/marfan/">https://www.pediatricheartnetwork.org/studies/marfan/</a>
<b># of Subjects with Available Clinical Data</b>	11583		800 (TCH patients, actively enrolling other centers)					5580	3516	12144	1035	871	1031	401		608
<b>Median Age</b> (in years)	62.7		13					57	39	36			45	39		14
<b>Age Min</b> (in years)	18		0					8	0	16	1	0	1	3		0.5
<b>Age Max</b> (in years)	106		45					90	97	81	98	75	96	83		26
<b># of Males</b>	7632		500					3764	1370	527	434	0	473	163		
<b># of Females</b>	3951		300					1661	1065	11627	405	871	351	239		
<b># of Type A Dissection</b> (repaired or not)	7735	20	6	300	100	400	100	9	150		123	38	9		5	0
<b># of Type B Dissection</b> (repaired or not)	3848	5	6	300	50	200	100	1	91		48	0	0		10	0
<b># of TAA Involving the Root or AA</b>	0		700	2000	250	1000	100	687	656		284	98			60	0
<b># of TAA Involving the Arch or Descending Thoracic Aorta</b>	0	10	50	500	50	300	100	18	495		61	0	75		10	0
<b># of Aortic Valve Surgery</b> (repair or replacement)	1381 (replacement)	80	200	2000	200	2000	100	1420	664		100	N/A	123		20	0
<b># of Ascending Aortic Surgery</b> (open repair)	6045	40	150	2000	200	1000	100	278	Data not available (replacement only)		167	N/A	79	7	5	12
<b># of Arch or Descending Aortic Surgery</b> (open repair, whether or not it involves the abdominal aorta)	3845	10	30	250	100	600	50	116	Data not available (replacement only)		104	N/A	62	2	0	
<b># of TEVAR</b>	1413	20	0	250		100	25	Data not available	Data not available		28	N/A	69	2	5	

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# of Subjects w/ Marfan Syndrome	374	3	200	50	220	40	75	14	845		0	0	0	0	70	608
# of Subjects w/ Loeys-Dietz Syndrome	25	1	70	15	154	20	25	3	104		550	0	0	0	30	0
# of Subjects w/ VEDS	11		50		29			1	149	107	21	0	0	402		0
# of Bicuspid Aortic Valve	266		300	1000	200	2000	200	3821	889		38	305	510		5	0
# of Subjects w/ Turner Syndrome	10	1	100	4		5	12	43	298		0	871	0	0	0	0
# of Subjects w/ Familial Thoracic Aortic Disease with Known Mutated Gene (TGFB1, TGFB2, SMAD3, MYLK, etc.)	0	1	20	300	25	100	10	0	369		1035	0	0	0	5	0
Actively Enrolling? (Y/N)	Y		Y					N	N	Y	Y	Y	N	Y		N
Are Images Available? (Y/N)	N		Y					N	N, novel evaluation available outside of BioLINCC (https://biolincc.nhlbi.nih.gov/studies/gentac/#novel-evaluation-of-gentac-images-is-available)	N	Y	Y	Y	Y		Y
Are Samples Available? (Y/N) <i>If Y, provide total number of samples.</i>	N		Y					Y	49773	Plasma, DNA	N	N	Y	N		Possibly
# of DNA Samples	N/A		60					5294	21865	819	NA	N/A	510			
# of Tissue Samples	N/A		0					0	1101		N/A	N/A	75			
# of Whole Blood Samples	N/A		0					0	0		N/A	N/A	N/A			
# of Plasma Samples	N/A		0					0	13083	167	N/A	N/A	N/A			
List of Publications <i>Include hyperlinks or send as attachment(s).</i>	105		None yet.						<a href="https://www.gentacalliance.org/publications/">https://www.gentacalliance.org/publications/</a>		5	1	1			