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For a good cause: Photographer to run N.Y. marathon to fight disorder

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CANTON — Aimee Benson is no stranger to marathons.

The 5-year Canton resident and entrepreneur, who this year launched her own business — Aimee Benson Photography — has participated in four 26.2-mile races.

Now, Benson is in training for one of the pinnacle events for marathon

runners — the ING New York City Marathon.

But this time around, Benson is running for a cause.

“It’s really exciting to be able to do something as simple as running and be able to help people,” she said.

Benson is one of 10 runners from across the country participating in the event representing the CdLS Foundation.

CdLS, or Cornelia de Lange Syndrome, is a rare genetic disorder present at birth that causes a range of physical and mental disabilities, as well as other medical conditions.

“It is very difficult to get awareness out,” said Gail Speers, development manager for the CdLS Foundation.

The Connecticut-based nonprofit serves as an advocacy group and resource center for families with children with CdLS.

“Many doctors have never even heard of it,” Speers said.

She said there are only about 2,500 children diagnosed with the disorder nationwide. The foundation estimates there are about 20,000 undiagnosed cases of CdLS.

Benson said she found out about the condition from a fellow marathon runner she met at a race in North Carolina.

The runner, New York resident Beth Smisloff, has a 20-year-old son with CdLS.

“Their relationship is incredible,” Benson said. “Seeing how they have managed

is incredibly inspiring to me.”

Smisloff is also running on the CdLS team in the ING Marathon.

Besides just raising awareness about the disorder, Team CdLS members are required to raise funds for the organization.

Speers said the CdLS Foundation is community partner of the race.

The ING New York Marathon organizers, the New York Road Runners, require community partners to generate a certain amount of donations to guarantee their spot in the event, she said.

Each Team CdLS member must raise \$2,500 to meet that goal.

To help meet that mark, Benson has launched a donation website. So far, Benson has raised about \$200, according to the site.

Benson said she is also working to organize a fundraiser using her business. She said she is working to organize a picture for donation event.

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