

World Sickle Cell Day 2021

(Antigua and Barbuda)

We at the Antigua and Barbuda Sickle Cell Association think World Sickle Cell Day is the perfect time to present our new venture. Thanks to kind-hearted sponsors like Mill Reef Fund, AUA and several compassionate, generous individuals who donated time, effort, money and brainstorming, our pilot project "**Sheltered Workshop for Sickle Cell Patients**" is now a reality.

This intervention is aimed at a group of our patients who have been hit the hardest by their disease. Every disease has a spectrum - asthma can be mild, moderate or devastating. The same applies to SCD. While some of our patients are doing beautifully well, others do not, no matter how hard we try. We have seasoned patients who are disabled according to the criteria set out in the Disability Act, and we have several young people who are sick too often to hold on to a job. Often, this results in depression, social isolation, financial hardship, hopelessness and restricted uptake of available care. We don't need to elaborate on these challenges - all of you know what we are talking about.

Our idea was to create a safe, positive environment where patients can explore and learn new skills without fear of being dismissed due to frequent absence.

For this pilot project, we opened the doors of the Sickle Cell Clinic (which is still not up and running, but that's another story for another day) on three days a week for six patients. Transportation to and from their homes is being provided (thank you, ABDF, for the first month!). Patients are at the clinic from 10 am until 4 pm and receive a token pocket money of 15.00 EC\$ for every day attended, which they may use to purchase their own supplies, if they want to continue at home, or which may simply help with groceries.

A "house mother" is supervising. Lunch is provided, as are all materials needed to learn various crafts: sewing and paper crafts, sculpting, drawing, pyrography, light gardening. Greeting cards, gift tags, Christmas ornaments, boutonnieres and corsages, paper weights -

the possibilities are endless. All these are items which can eventually be sold and create a modest income, once the patients have become proficient.

In addition, we have regular sessions teaching and practicing mindful breathing and will eventually start brief seminars about various aspects of SCD in order to improve self-care.

All this is very new. We started on June 9th 2021 with Mandala colouring books and painting-by-numbers, both unthreatening, relaxing and satisfying. We moved on to creating greeting cards and paper-mache. The participants' reactions have been overwhelming, heartwarming and humbling.

Our patients, some of them struggling with depression, loved it from Day One. They look forward to each session, to each other's company, to doing something that has visible results. They look out for each other, encourage each other. If one doesn't feel well, they are all there to reassure and soothe. Since it's a some-day-to-be clinic, we have two beds, which can be used when needed. There is no pressure, no demand to perform, just opportunities, positive vibes and understanding.

Not only did patients ask to take their Mandala colouring books home; it turns out that they hate missing a day. As a patient in a good amount of pain said: "I'm still coming tomorrow. I'll just lie down there; I enjoy the company. And it's much better than being in pain alone at home."".

When we planned this project, we were hoping for all the obvious benefits, but this last bit? We did not expect that. We could not possibly be more pleased.

