Greetings to our friends, “neighbors,” and supporters! We are writing to update you on an eventful year for the PALTOWN Development Foundation, and to give you a preview of things on tap for 2019.

This year saw tremendous growth for our online colorectal cancer community, COLONTOWN. In addition to welcoming many new neighbors and creating new neighborhoods, we were able to put resources into building processes and structures that will allow COLONTOWN to continue to serve more patients and caregivers over the next several years.

Also this year, we launched our Empowering Patient Leaders Workshop program, which plays a critical role in both the ongoing sustainability of COLONTOWN and in our core mission, as we explain below.

On the organizational side, although PALTOWN remains in “startup” mode, with two contract staff and a very lean operating budget, we have also taken substantial steps towards becoming a mature enterprise by building on our first efforts in 2017 to fundraise, secure grant funding, and explore additional modes of supporting the work PALTOWN does. Finally, we have expanded both our corps of dedicated and trained community volunteers, without whom COLONTOWN would not thrive, and our Board of Directors, which now includes several medical professionals and additional patient representatives.

It’s been a busy year! 2019 looks to be even more exciting, and we hope you will be there with us as we meet the challenges ahead. If you have thoughts or feedback about any of our current or planned activities, we’d love to hear from you. Reach out to Erika at ebrown@paltown.org, or Nancy at nseybold@paltown.org.

VALUES AND MISSION

PALTOWN’s mission is to empower patients and caregivers by creating disease-specific communities to address information needs and social isolation through training, technology, and developing purpose-driven leadership.

Our program offerings — at present, COLONTOWN, and the Empowering Patient Leaders Workshops — deliver on this mission through a clear-eyed focus on our core values:

- **AUTHENTICITY**: all our offerings are presented by patients and caregivers themselves
- **EDUCATION**: much of the discussion we foster is structured around accurate, contextualized information about treatment options, clinical trials, and symptom management
- **EMPOWERMENT**: through our commitment to the primary role of patients and caregivers in not only their own cancer decisions, but in the management of COLONTOWN and the Workshops, we empower our constituents to be advocates, and leaders.
- **HOPE**: through education and empowerment, and community, comes hope. We see this every day, powerfully, in the lives and the words of our COLONTOWN neighbors.
PROGRAM OFFERINGS

COLONTOWN, our online community for colorectal cancer patients and caregivers, grew by 25% in 2018. We now have over 4000 members, and thanks to a new onboarding process, have also doubled our intake success rate. Two volunteer deputy mayors now manage the onboarding process, one for patients, and one for caregivers, ensuring each new member gets introduced to the community and connected to other members.

As COLONTOWN has grown in members served, it has also grown in its breadth of offerings. The unique model of COLONTOWN offers members not only a central “DOWNTOWN” community, but dozens of niche “neighborhoods.” These secret Facebook groups are focused on disease stages, the differing types of treatments, and special interests - such as CRC clinical trials, young-onset CRC patients, and local support. Every neighborhood is led and nurtured by a Community Manager (or several), themselves living the specific experience of that particular group. In 2018, we expanded the neighborhoods under the COLONTOWN umbrella to over 100. Two main areas of growth were the clinical trials neighborhoods - segmented by tumor type and mutation status, which often determine which specific trials may be an option for a patient - and the local “CREWS,” where TOWNies living nearby can connect both online and offline.

Here’s the current list of neighborhoods. Remember, each one of these groups is managed by one or more volunteers from the community. These volunteers coordinate their efforts in their own “Council” neighborhood, helping Erika manage the community as a whole. It is a tremendous labor of love for our Neighborhood Administrators, and one of the great strengths of COLONTOWN.

COLONTOWN NEIGHBORHOODS

COLONTOWN DOWNTOWN: Central group, all members belong

AGES AND STAGES
- 1st Street (stage i patients)
- 2nd Avenue (stage ii patients)
- 3rd Lane (stage iii patients)
- Four Corners (stage iv patients)
- River Valley (end stage patients)
- Youngstown (patients diagnosed under 40)

BLUE LIGHT SPECIALS
- Flora Garden (fecal transplantation)
- HAI Pump People (HAI for liver mets)
- Hipec Heights (HIPEC for peritoneal mets)
- Live Wire (neuropathy from chemo)
- Lonnie Den (LONSURF chemo)
- Mighty Y-90 (y-90 for liver mets)
- Reconstruction Zone (reconstructive surgery in vaginal area)
- Reversal Roundabout (ostomy reversal)
- StivargaVille (STIVARGA chemo)
- Stoma City (all ostomies)
- The Late Show (patients with long-term treatment after effects)

CAREPARTNER COVE
- Beyond the Threshold (for those whose patients have passed away)
- Carepartner Corner (for primary carepartners)
- Family Circle (for family members)
- Stage IV Carepartners (for stage iv only)
- Teen COLONTOWN (teen family members)

INTERNATIONAL CREWS
- Straya (Australia)
- The Darmstadt CREW (German language)
- True North CREW (Canada)
- Villa Colon (Spanish language)

cont. >>
MALADIES, PROPENSITIES, AND LOCATIONS
- Analwise (anal cancer/patients only)
- The Attic (brain mets)
- Cecumburgh (cancer originated in cecum/patients only)
- ChekPoint (Chek2 mutations)
- FAP Family (FAP/patients and family)
- Honor Thy Appendix (cancer originating in appendix/patients only)
- IBD Alleyway (IBD, colitis, crohn’s/patients only)
- Jelly Belly Place (mucinous cancer)
- Legosland (bone mets)
- Liver Lovers’ Lane (options for liver mets treatment)
- Lungston (lung mets)
- Lynchville (lymph syndrome/survivors and “pre-vivors”)
- Poopchute (colon cancer/patients only)
- Rectalburgh (rectal cancer/patients only)
- Transplantation Station (live donor liver transplants for crc)

SPIRITUAL SPOTS
- COLONTOWN Kibbutz (Jewish)
- Crescent and Star Centre (Muslim)
- Spiritual Center 4 All Faiths (primarily Christian)

THE CIRCUS
- Billing Office (insurance issues)
- Crafting 4 Healing (arts and crafts and fun)
- Healthy Gut Cafe and Fitness Center (dietary and fitness support)
- Merlin’s Majic and Laffs (be silly here)
- Palliative Pathways (palliative care)
- Planning Plaza (end of life planning, wills, finances)
- Poker Group (men only)
- PTA (patients with young children)
- Singletons (singles only)
- Skeptics Overpass (nonbelievers)
- Tough Chicks (women only)

THE NEWS BUREAU (PUBLIC GROUPS)
- New Times
- Bloggers Haven (cancer-related blog posts and links)
- Public Library (resources)

TOM’S CLINIC
- CRC 101 (scientific fundamentals of colorectal disease)
- Tom’s Anal Cancer Trials (all anal cancer trials)
- Tom’s BRAF+ Treatment Clinic (BRAF, MSS)
- Tom’s Car-T Club (Car-T trials)
- Tom’s Chek2 Club (Chek2 mutations)
- Tom’s Her2 Clinic (HER2)
- Tom’s MSI-H Clinic (MSI trials)
- Tom’s MSS Clinical Trials 4 CRC (MSS, KRAS mutations trials)
- Tom’s NIH Lounge (T-il and other NIH trials)

USA CREWS
- Atlanta
- Badgerburgh (WI)
- Bay Area Crew (SF)
- Bayou/Gulf Crew (LA and Gulf Coast)
- Beantown (Boston area)
- Big Apple (NY)
- Bluebonnets (TX)
- Capital City (MD, DC, VA)
- Carolina (NC, SC)
- Cornhusker Crew (NE)
- Field of Dreams (IA)
- Glitter Gulch (NV)
- Hollywoodland (So Cal)
- Indy Crew (Indianapolis)
- Jersey Strong (NJ)
- Liberty Bell (PA)
- Mayo (Mayo Clinic/Rochester)
- Middle of the Map (KC)
- Mile High (Denver)
- Motor City Crew (Detroit)
- Rock n Roll (Cleveland)
- Snow Country Crew (UT)
- Sunshine State (FL)
- Thunder Alley (OK)
- Trailblazers (Pacific NW/Portland)
- Treasured State (MT)
- Twin Cities (MN)
- Windy City (Chicago)
Empowering Patient Leaders Workshops

PALTOWN launched its Empowering Patient Leaders Workshops in 2018, hosting two educational events for COLONTOWN members. This program trains participants to become educated, become engaged, and become leaders; it stems directly from our core values.

Over time, the Workshop Program will create a substantial group of colorectal cancer patients and caregivers versed in current treatment options, the clinical trials system, and community management best practices. As the graduates of the inaugural 2018 program have demonstrated, participants in the Workshop program will translate their experiences into increased engagement with the COLONTOWN community, directly benefiting the thousands of “neighbors” in their groups. As a result, all COLONTOWN members will have access to a broader range of information about treatment options, including awareness of clinical trials as an important treatment option for patients along the spectrum of disease stages.

In 2018, PALTOWN hosted two workshops for COLONTOWN members. The inaugural workshop brought current COLONTOWN community leaders and leadership aspirants together to explore best practices, brainstorm how best to grow the community globally, and refine the initial training curriculum.

Components of this curriculum formed the basis of the second workshop, hosted by the University of Colorado’s Anschutz Cancer Center. At this workshop, sessions included educational programming about immunotherapy, tumor markers, and the clinical trials ecosystem, along with community management best practices. Faculty included both Dr. Christopher Lieu from Anschutz and several graduates of the inaugural workshop, some of whom bring professional scientific expertise along with their life experience as CRC patients.

In 2019, we plan to expand the Workshop Program to 3 events: Boston (May), Chicago (August), and San Diego (November). We see this program as a critical element of our mission, as it not only creates empowered patients and caregivers, and directly benefits the overall community, but will also provide the genesis for additional communities for other disease spaces in years to come.

Patient Leader Steve Schwarze leads a session on clinical trials resources

PALTOWN’s first Empowered Patient Leader Class, June, 2018

PALTOWN’s second Empowered Patient Leader class, October, 2018
FINANCIAL SNAPSHOT

In 2018, PALTOWN applied for and received its first grant, from Taiho Oncology to support the Empowered Patient Leaders Workshop. We also received a number of corporate sponsorships and donations to support both COLONTOWN and the Workshop Program. The largest source of support, however, came from individual donations, as the chart below demonstrates. Reflecting our Facebook-centric presence, fundraisers run by PALTOWN supporters and COLONTOWN members on Facebook netted over $41,000 in 2018, including a hugely successful fundraiser focused on Giving Tuesday in November.

Our expenditures include staff (Erika Brown and Nancy Seybold), basic operations, fundraising efforts, and, of course, our programs, as described above. These comprise the largest percentage of our 2018 expenditures.

It is important to note that the majority of our fundraising was via Facebook fundraisers; this list is only a small portion of our individual donors. Facebook provides a very easy and successful mechanism for individuals to create fundraisers and to collect funds for causes. We are grateful for this, but Facebook’s reporting mechanisms out to the organizations receiving the funds are very rudimentary. We did have an extraordinary response to our call to raise funds for Giving Tuesday, the Tuesday after Thanksgiving. Hundreds of donors responded, giving through fundraisers created by the COLONTOWN members listed below. We’d like to make a fuss over them, because — as these numbers show — they made a tremendous contribution to our success this year.
DONORS

GRANTS
Taiho Oncology

CORPORATE / INSTITUTIONAL SPONSORS
Exact Sciences
Mitra RxDx
Scripps
Ignyta
Medical Imaging & Technology Alliance
Magruder & Associate
Mission Brewery
Submittable

AFFILIATE ORGANIZATION SPONSORSHIPS
Colon Cancer Coalition
Fight CRC

INDIVIDUALS

$1000 AND OVER
Teah Bennett
James Craft
John Eckstein
Deborah Goldberg
Kelly Nelson
Jennifer O’Dell
Julie Wrigley

$500-999
Diane Bendtsen
Robin Braverman
Valerie Frye
Jan Lalli
John Hamelink
Shirley Schwarze
Kenneth Shapiro
Steven Williams
Kriss Wittmann
Chris Yoo

$250-499
Donna Buttenhoff
Lisa Cecil
Lisette Dapena
Paul Donovan
Lauri Ellis
Gregg Gordon
Violet Kuchar
Gerald Lelais
Linda Plaster
Bryan Roberts
Lisa Scenti
Marianne Walker

GIVING TUESDAY FUNDRAISER

MAYOR’S CIRCLE
RAISED OVER $1000 EACH
Chelsea Boet
Erika Brown
Amanda Coleman
John Hamelink
Jenn O’Dell
Charise Parsons
Elaine Ferrer Ramirez
Steve Schwarze

HONOR ROLL
Kim Austin
Diane Bendtsen
Tony Black
Robin Braverman
Lisa Brown
Dana Cardinas
Karen Clark
Kathleen Clark
Tracy Compton
Tavla Crumpler
Lisette Dapena
Kirsten Dykstra
Lynn Doll
Meredith Flood
Manju George
Lauren Hindman
Molli Hood
Amy Joosten-Butler
Roxane Kraus
Violet Kuchar

Maria Kucharek
Amy Kuehn
Michele Leslie
Blann Lutken
Sheela Mageela
Marcy Marsh
Annette Martinez
Nancy Matulef
Jan Mayberry
Kelly Nelson
Erin Nevers
Janie Peskin
Catherine Salgado
Heather Stoker
Holly Sullivan
Rachel Topper
Molly Ulrich
Andi Vanderhoek
Courtney Webster
VOLUNTEERS

Our volunteers are quite literally the magic that makes COLONTOWN work. Running a virtual town with thousands of denizens and over 100 neighborhoods is an immense effort. Managing all of this via Facebook, which provides no tools for Erika’s novel creation of “Groups of groups,” adds a layer of complexity and hassle that volunteers must manage. As part of our efforts to steer COLONTOWN towards self-governance (looking ahead to the day when we start another community), we recently created a Community Standards Council comprised of the core set of volunteers who have committed to major roles in the daily administration of the community.

Diane Bendtsen  
Community Onboarding, Patients Lead Onboarding Contact

Jennifer O’Dell  
Community Onboarding, Caregivers Lead Onboarding Contact

Stacey Runfola  
Admin Recruiting/Training (Patient & Caregiver)

Steve Schwartz  
Clinical Trials Neighborhoods

Manju George  
Science & Education

Lari Johnston  
US Neighborhood CREWS

Kim Austin  
Neighborhood Councils

Chelsea Boet  
Consulting Physicians Liaison; PALTOWN BOD Board Rep

Robin Braverman  
BOD Liaison to CarePartner and Patient Organizations

Fernando Ruiz  
Media Production; Branding

Conradin Döbeli  
International CREWS & Development

BOARD OF DIRECTORS

PALTOWN is blessed with a working Board of Directors, which expanded in 2018 to 15 members. Our Inaugural Chairman, John Eckstein, stepped down from his executive role, and the board elected Trevor Barlow as the new Chair. Linh Nguyen remains Treasurer, and Nancy Seybold is serving as Corporate Secretary as well as COO. Erika Brown is our CEO. Existing board committees - Strategic Partnerships, Finance and Operations, and Executive — now have formal charters. We have added a Development committee, chaired by new board member Howard Brown, who brings long expertise in this area. Our new additions include:

Dr. Chelsea Boet  
Practising physician and stage iv crc patient in active treatment

Howard Brown  
Entrepreneur, cancer survivor, and stage iv crc patient in active treatment

Dr. Chris Heery  
Medical oncologist and Chief Medical Oncologist, Bavarian Nordic

Dr. Kamala Maddali  
Vice President, Biopharma Collaborations & Companion Diagnostics, Cancer Genetics

Dr Chris Yoo  
Biomedical informatician and entrepreneur
LOOKING AHEAD TO 2019

This year promises to be one of growth for PALTOWN. We will host 3 Empowering Patient Leaders Workshops, and will continue to expand COLONTOWN in both membership and offerings. We are launching an Affiliate Program to build relationships with other patient and caregiver-focused organizations, and hope to begin other new initiatives as resources allow. We cannot do this without our many supporters!!! Please visit us at paltown.org to learn more about the people and the programs of PALTOWN, and to join us in the important work of the Foundation.

Regards,

Erika Brown
CEO, PALTOWN Development Foundation