

CTMB Meeting August 7, 2019

The Charitable Trust Management Board (CTMB) of the Newfoundland Club of America Charitable Trust met via teleconference on August 7, 2019. Clyde E. Dunphy called the meeting to order at 7:32 p.m. CDT. Members present were Clyde Dunphy, John Cornell, Mary Lou Cuddy, Denise Hatakeyama, Lori Littleford, Chris Plum, Roger Powell, Mary L. Price, and Mary Jane Spackman.

Lori moved to approve the minutes of July 3, 2019 as corrected. Denise seconded. Motion passed unanimously.

Chairman's Report: Clyde contacted Carla Gengler and she is willing to write an article on RMB (Required Minimum Distribution) for *Newf Tide*. In regards to the \$1,084.00 profit from H&L's health clinic at the National, John moved to return these funds to the Education Grant fund per policy, Mary Jane seconded. Motion passed unanimously.

Secretary's Report: Mary Jane reported the talk she gave on the Health Challenge at the Southeastern Newfoundland Club's Annual Meeting in Greenville, South Carolina was well received.

New Business: Dr. Brian A Scansen, DVM, MS, DACVIM, Associate Professor of Cardiology Service Head, Cardiology & Cardiac Surgery, Colorado State University joined the meeting at 8:00 p.m. CDT to discuss the following proposal with the CTMB:

Proposal Highlights:

- Evidence-based decisions are necessary to scientifically advise appropriate care of dogs with heart disease.
- Multicenter studies are needed to enroll sufficient patients to generate appropriately powered evidence, but such studies are complicated by cost and logistical hurdles.
- Establishing a consortium of veterinary cardiologists, at both private and academic sites, organized under a central entity with low barriers to case enrollment would facilitate well-designed studies and advance medical decision-making for dogs with heart disease.

- Subaortic stenosis is a disease that lacks scientific evidence to guide therapy or advise clients, and represents a pragmatic question to answer under the paradigm of a national consortium.

Clinical Trials Infrastructure:

Human medicine is guided by large studies that compare different treatment options (often to a placebo or inert substance) to validate or refute therapeutic benefit. These are typically funded by the federal government (NIH) or pharmaceutical companies. Veterinary medicine does not have federal support to run such studies and pharmaceutical companies only support studies of drugs for which they control the intellectual property. Most clinical trials in veterinary medicine are therefore limited to single hospitals, are small in scale, and are underpowered meaning that an insufficient number of dogs are enrolled to draw meaningful conclusions.

With today's technology and appropriate infrastructure, information from large numbers of dogs being treated by cardiologists across the country can be obtained and digitally stored and analyzed. This proposal seeks funding to establish and support a Veterinary Cardiology Clinical Trials Center that would design and coordinate studies of dogs with SAS and other heart conditions across the country. Veterinary cardiologists would be able to enroll dogs diagnosed in their practice with minimal local effort, as the central consortium would collect relevant demographic and disease data, input these data into a central database, randomize the dog to a placebo or active therapeutic substance, and mail the appropriate pills directly to the client. The work of an entity of this kind would provide novel information on the outcome of dogs with heart disease, while coordinating scientific studies of therapy with large numbers, providing evidence to inform daily treatment decisions.

A national clinical trial consortium for studying diseases of dogs has precedent, with the Comparative Oncology Trials Consortium serving as a leading example where federal funding has been allocated to coordinate and support well-designed studies of cancer in client-owned dogs.^{1,2} Further, in the spring of 2017, a survey was distributed to members of a veterinary cardiology list serve to gauge interest in the development of a national consortium for clinical trial development in veterinary cardiology. 1678 Campus Delivery | Fort Collins, Colorado 80523-

1678 | (970) 297-1274 | fax: (970) 297-1275 cvmbc-clinsci@colostate.edu |
www.cvmbc.colostate.edu/clinsci/ Termed INSPECT, an acronym for the Initiative
for Simple and Pragmatic End-point Clinical Trials

Subaortic Stenosis in Dogs: The challenges facing the veterinarian when presented with a dog suffering from SAS are twofold: there are no therapies proven to have benefit, and predicting the outcome of an individual is challenging given sparse data on the natural history of this disease. There are four studies that provide some data on the natural history of SAS.⁴⁻⁷ The two published prospective studies^{5,6} were composed of small numbers (at most 22 dogs per treatment group) and did not compare medical therapy (atenolol) to a placebo, while the retrospective studies^{4,7} also analyzed small numbers of dogs and suffer from the flaws inherent to a retrospective design. Advising the family who shares their life with a SAS dog is therefore difficult and frustrating. We need investment to better understand what therapies delay adverse events (heart failure and sudden death) in dogs with SAS as well as a better understanding of the natural history of this condition in a large population.

Most cardiologists currently prescribe atenolol for dogs with severe SAS in the preclinical state, though there are no studies that have determined a beneficial or adverse effect of atenolol on the disease. The first study that would be run by the Veterinary Cardiology Clinical Trials Center would be to assess the effect of atenolol versus placebo in a national, multicenter, randomized, placebo-controlled, double-blind study of dogs with severe (gradient greater than 80 mmHg) SAS. In brief, dogs with severe SAS would be randomized into the study once an echocardiogram documents disease. Cardiologists in both private and academic practice would provide clients with information on the study at the time of first diagnosis. Local impact on the practice would be minimal as informed consent, randomization, and drug therapy would be provided from the central office. Follow-up cardiac evaluation would be at the discretion of the attending veterinarian and neither dictated nor funded by the study as the goal is to enroll a large, representative sample of dogs with this disease and follow their natural history with or without atenolol. Clients would be requested to submit biannual

reports on the overall health of their dog and to adhere to the daily prescribed medication.

Preliminary estimates of sample size rely on historical data that 50% of dogs with SAS will die by 5 years of age.⁴⁻⁷ A clinically relevant advantage of atenolol to placebo would be if 70% of dogs survived to 5 years of age. Considering this differential survival rate, a type I error estimate of 0.05, and a type II error estimate of 0.1, calculations suggest a total sample size of 256 dogs is required. Presuming a 10% rate of dogs lost to follow-up, we suggest a target enrollment of 280 dogs randomized 1:1 to atenolol vs. placebo. From the INSPECT survey, 133 cardiologists answered that they would be willing to submit cases and when asked how many new cases of severe SAS were seen in their practice the survey suggested that a sum total of 600 to 750 new cases of severe SAS are seen by these cardiologists each year. These data support the notion that sufficient buy-in from the cardiology community can be expected and that the desired sample size can be achieved in a reasonable timeframe.

Projected cost \$ \$95,720 per year for a term of five years, total cost \$478,600.00.

Dr. Scansen fielded a variety of questions from the CTMB, including the natural course of SAS which is not defined, the advantage of large scale multi-facility studies, the support of cardiologists for this study, the goal of the evidence provided, the ethics of placebo for dogs impacted by SAS, the role/detail of the data collection, as well as other questions.

Dr. Scansen left the meeting at 9:00 p.m. CDT.

Following Dr. Scansen's presentation, it was the consensus to move forward with support for this study. A sub-committee will be formed to track the future of this study and to investigate fund raising ideas.

Clyde reported that Frank J. Rooney, former IRS attorney currently in practice in Virginia, is looking into the charity registration in Virginia.

Marylou moved to approve the Third Party Advertising on Social Media policy as presented by Chris Plum, Lori seconded. Motion passed unanimously. Document follows:

Fundraising and Advertising by Third Parties for the NCA Charitable Trust

The mission of the Newfoundland Club of America's Charitable Trust is to secure donations, to manage and distribute funding in support of research grants to study health issues affecting Newfoundlands, to provide necessary monetary aid for Newfoundland rescue assistance, and to award educational scholarships to junior Newfoundland fanciers.

Fundraisers that benefit the Newfoundland Club of America's Charitable Trust must reflect positively on **the** mission of the Charitable Trust. The NCA Charitable Trust Management Board reserves the right to decline any fundraising **or** advertising proposal that is not in line with the mission of the Charitable Trust.

Instructions for Third Parties

Third Parties (people who are not members of the Charitable Trust Management Board or the Trustee) may advertise fundraisers on the Charitable Trust's social media channels (such as Facebook) with approval from the Charitable Trust Management Board. Such parties must fill out a form (attached and available online at: _____) and send all required materials in final form to the administrator of the Charitable Trust's social media channels. The proposed fundraising or advertising will be reviewed by the page administrator under the supervision of the Charitable Trust Management Board. Upon approval, the fundraising or advertising will be made public. If the administrator determines the content to be inappropriate, then the fundraising or advertising will be rejected. The decisions of the administrator are final.

Advertising for 3rd party events and fundraisers must reflect the NCA Charitable Trust as a beneficiary and not as the organization that is conducting the event or fundraiser *e.g.* "proceeds from XYZ Golf Tournament will benefit NCA Charitable Trust"). Advertising for a specific Charitable Trust program must state such clearly (*e.g.* Fundraiser for NCA Rescue, Proceeds benefit NCA Health Challenge).

Approved 3rd Party fundraisers will be listed in the Giving Center of the Charitable Trust website and acknowledged in NewfTide.

Any use of the Charitable Trust, NCA Rescue Network or NCA Health Challenge logos must be approved by the Charitable Trust Management Board. Electronic Logo files will be provided to approved 3rd Party Fundraisers upon request.

Ads will not be posted or published until payment is received. If payment is by check, made out to the Newfoundland Club of America in US dollars drawn on a U.S. bank, it must accompany ad copy. Payments for ads may also be made through PayPal (www.ncacharities.org) or Stripe (NCA member portal).

Electronically-submitted photos should be screen resolution (72 dpi). Square images between 800 x 800 and 1000x1000 pixels display best without cropping. Text should be provided separately from ad images, text contained in images should cover less than 20% of the image. Ad text may contain links to 3rd Party sites.

Completed ads should be submitted at least 7 days before requested placement time. Postings will occur weekly.

Fundraising campaigns are allowed fresh ad content weekly.

Vendors and other supporters of the Charitable Trust may also have paid advertising postings.

Fees

Because the Charitable Trust raises funds to support its mission, advance payment is required for all fundraising and advertising. If fundraising and advertising is for a 3rd Party fundraising campaign, the amount of the initial payment can be deducted from the actual proceeds of the campaign. Within 30 days of the close of a 3rd Party fundraiser, event or campaign, the organizers must submit funds, payable to NCA Charitable Trust with appropriate documentation for publication in Newf Tide (see attached description of requested documentation).

For general advertising, a contribution of \$20 will entitle the advertiser to have one posting each month; \$40 for two months, up to \$240 for a full year, etc.

The CTMB does not accept any advertising that does not comply with Facebook Community Standards, including puppy sales. CTMB will not accept any advertising that promotes a political party, candidate or potential candidate.

Application

Third Party Fundraiser and Charitable Trust Advertising

Organization Name:

Date:

Contact Name:

Email:

Mailing address:

Phone:

Website: (if applicable)

NCA Member: Yes No

Description of 3rd Party Event or Activity:

Start date:

End date

FINANCIAL INFORMATION

So that Charitable Trust Management Board can assist you in the production of a successful event, please indicate how you will generate revenue for NCA Charities:

Ticket Sales/Entry Fee

Auction

Drawing/Raffle

Donation Drive

Online Campaign

Other

What percent of gross proceeds (sponsorship, drawing, tickets, fees, etc.) will be donated?

_____ % Anticipated GROSS event revenue: \$

Anticipated NET event revenue: \$

Will this be an annual event to benefit NCA Charities? Yes No

The fee for an initial posting is \$20. For General advertising the fee covers 1 posting, additional reposts or posts of new ads will be accepted monthly. For 3rd Party fundraisers the fee covers 1 weekly post for the duration of the campaign.

Notes (if any):

For NCA CTMB administrator use only:

Fee paid amount:

date:

Approved by:

Treasurer's Report: Mary L. Price reported the Trust's cash balance of August 4, 2019: Newfoundland Health Challenge (NHC): checking account—\$19,818.45; SAS Research Fundraising- \$7,671.31; invested in CDs—\$ 20,000.00; Money Market Account--\$25,965.63; MS Brokerage Account-- \$74,698.98 Health Challenge total—\$ 148,154.37, Rescue Fund checking account—\$13,711.74; Barrister Fund-\$ 1,725.00; Barrister Fund for Seattle NC Rescue area - \$10,000.00 Money Market Account-\$31,124.06; MS Brokerage Account- \$307,807.68; Rescue total—\$364,368.48. Scholarship Checking- \$5,583.26 ; MM Account- \$10,488.43; Scholarship Total- \$ 16,071.69; Endowment Fund: Morgan Stanley unrestricted: \$33,914.15; Education Fund-MM account \$5,070.23; Endowment Fund Unrestricted - MM Acct.- \$1,391.92; Trust Management Checking - \$6,163.94; MM Acct.- \$1,073.95; Trust Management Total- \$7,237.89. **Total Charitable Trust—\$ 576,208.73.**

(Newfoundland Health Challenge adjustments; Newfoundland Health Challenge – \$73,455.39; AKC Canine Health Foundation Donor Advised Fund as of 6/30/2019 \$24,195.05; \$0 reserved for Grants for total NHC balance of \$97,650.44).

(Scholarship adjustments; Reserve for scholarships - \$10,091.90; Funds available - \$5,979.79)

Rescue: The producer of the Central Illinois 8 surrendered his last five Newfs to Rescue. Upon vetting, one had to be euthanized due to temperament, the other 4 are in foster care.

The next meeting of the CTMB will be Wednesday, September 4 at 6:30 CDT.

Mary Jane moved to adjourn at 8:37 p.m., CDT. Lori seconded. Motion passed unanimously.