1953 - 1962

Frank Grant, Telegram

As blood plasma flows into his arm and slowly brings strength back to his body, Stephen Christmas lies the Hospital for Sick Children and talks to his mother. Doctors have diagnosed his afflication as a form o mophilia and have named it Christmas Disease after Stephen.

EARLY MILESTONES

2ND CENTURY
Rabbinical rulings exempt boys from circumcision if two brothers died from bleeding.

11TH CENTURY
Reference to bleeding condition in the writings of Arabic surgeon, Albucasis.

12TH CENTURY
The rabbinical ruling exempting boys from circumcision because of bleeding is extended to half-brothers with the same mother, in appreciation of the hereditary nature of the condition.

1803 "An account of a hemorrhagic disposition exisiting in certain families" is described by Dr. John Conrad Otto of Philadelphia.

1828 First use of the word "hemophilia" by Hopff at the University of Zurich to describe inherited bleeding disorders.

1840 First use of a blood transfusion to control bleeding in hemophilia, described by Samuel Lane in *The Lancet*.

1853 Leopold, son of Queen Victoria, first "Royal" to have hemophilia.

1904 Alexis, heir to the Russian throne, is born with hemophilia.

1936 First plasma transfusion to treat hemophilia.

1939 Kenneth Brinkhous identifies "antihemophilic factor", now called factor VIII, as the deficiency in people with hemophilia.

1944 Edwin Cohn, an American biochemist, develops fractionation, the process of separating plasma into its different components.

1948 First hemophilia dog colony in Chapel Hill, North Carolina.

1952 Researchers describe a new type of hemophilia, now known as factor IX deficiency. It is called Christmas Disease after the first patient, Stephen Christmas, of Toronto.

1952 Thromboplastin test developed to measure FVIII.

1952 Coagulation cascade discovered.

PREMIÈRES ÉTAPES IMPORTANTES

IIe SIÈCLE
Une règle rabbinique exempte un garçon de la circoncision si deux de ses frères n'y ont pas survécu à cause du saignement.

XIe SIÈCLE
Référence au saignement dans les écrits d'un chirurgien arabe, Albucasis.

XIIe SIÈCLE
La portée de la règle rabbinique qui exempte les garçons de la circoncision en raison du saignement est élargie aux demi-frères ayant la même mère, ce qui reconnaît la nature héréditaire de cet état.

1803 « Une disposition hémorragique existant dans certaines familles » est décrite par le Dr John Conrad Otto, de Philadelphie.

1828 Première utilisation du mot « hémophilie » par Hopff à l'Université de Zurich, pour décrire les troubles de coagulation héréditaires.

1840 Première utilisation d'une transfusion sanguine pour contrôler le saignement chez un hémophile, décrit par Samuel Lane dans *The Lancet*.

1853 Léopold, fils de la reine Victoria, premier membre d'une famille royale atteint d'hémophilie.

1904 Alexis, héritier du trône de Russie, naît avec l'hémophilie.

1936 Première transfusion de plasma pour traiter l'hémophilie.

1939 Kenneth Brinkhous identifie le « facteur antihémophilique », maintenant appelé facteur VIII, comme étant l'élément manquant chez les hémophiles.

1944 Edwin Cohn, un biochimiste américain, met au point le fractionnement, un processus qui permet d'isoler les différents composants du plasma.

1948 Première colonie de chiens hémophiles à Chapel Hill, en Caroline du Nord.

1952 Les chercheurs décrivent un autre type d'hémophilie, soit le déficit en facteur IX. Il s'agit de la maladie de Christmas, nommée ainsi d'après le premier patient, Stephen Christmas de Toronto.

1952 Le test de thromboplastine est mis au point pour mesurer le facteur VIII.

1952 Découverte de la cascade de coagulation.

In 1952, Stephen Christmas was the first person in the world to be diagnosed with factor IX deficiency, then called Christmas Disease. He grew up in Canada and played a key role in preparing the Archival Study to support the CHS request for HIV compensation in the late 1980s.

En 1952, Stephen Christmas a été la première personne au monde à recevoir un diagnostic de déficience en facteur IX, appelée alors maladie de Christmas. Il a grandi au Canada et a joué un rôle clé dans la préparation de l'étude d'archives qui appuyait la demande de la SCH en vue d'obtenir une compensation pour le VIH à la fin des années 1980.

TRIBUTE TO THE CHS FOUNDER, FRANK SCHNABEL

David Page

As a young boy with hemophilia in Montreal in the 1950s, whose parents and grandparents were active in the Canadian Hemophilia Society, I grew up hearing about 'Frank'. In my house he was portrayed as a sage. I knew he wasn't a doctor, yet he was the one whose words counted. "Frank says there's a new blood product. It means surgery could be safe." "Frank says he's getting his plasma as an out-patient—he's not being admitted to hospital anymore." "Frank says we need to push for comprehensive care."

I knew Frank had hemophilia like I did, yet he was doing the most amazing things. He was the Consul-General for Costa Rica—this was very mysterious—and was always traveling around the world. He had a huge office at the top of Montreal's tallest skyscraper—even more impressive—which I visited on occasion. (I now know he worked as an investment analyst at The Imperial Trust.) And, best of all, he had season tickets for the Montreal Canadiens hockey team and, when I was very lucky, invited me to go with him. Watching the game, we discussed everything under the sun, including hemophilia. It was in researching this article that I came across these words of Frank's from the 1960s.

> *"I wanted to be like everyone else. I didn't want to be different. So I never told anyone what was wrong with me. Then it occurred to me that if all hemophiliacs hid their problem, how could we ever expect to make any progress? I felt we had to educate people about hemophilia, and then push, and push hard, for better treatment and more career opportunities. So I went to the other extreme and just refused to stop talking about hemophilia."*

I remember my parents' pride that this young Montrealer, who had rounded up patients, parents and physicians to found the Canadian Hemophilia Society in 1953, went on to create the World Federation of Hemophilia ten years later, with six founding National Members—Argentina, Australia, Belgium, Canada, France and United Kingdom. And, only five years later, he brought

FRANK SCHNABEL : FONDATEUR DE LA SOCIÉTÉ CANADIENNE DE L'HÉMOPHILIE

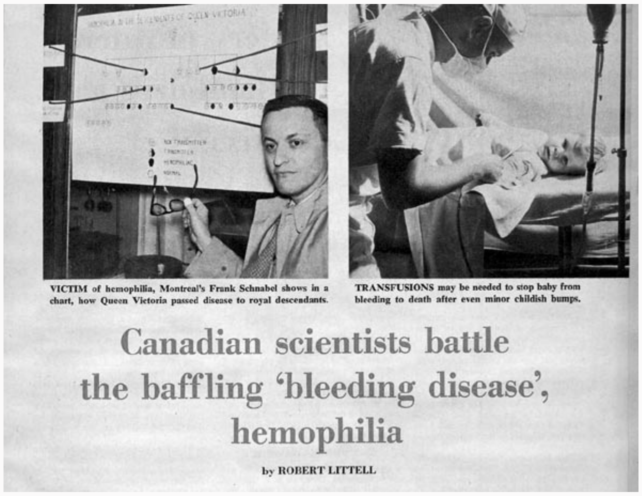
En tant que jeune garçon hémophile habitant à Montréal dans les années 1950, et dont les parents et grands-parents œuvraient activement au sein de la Société canadienne de l'hémophilie, j'ai grandi en entendant parler de « Frank ». Chez nous, on le considérait comme un sage. Je savais qu'il n'était pas médecin, mais c'était celui dont la parole comptait. « Frank dit qu'il existe un nouveau produit sanguin. Cela veut dire qu'une chirurgie pourrait être réalisée en toute sûreté. » « Frank dit qu'il obtient son plasma en consultation externe — on ne l'admet plus à l'hôpital pour cela. » « Frank dit qu'il faut faire des pressions pour obtenir des soins complets. »

Je savais que Frank était hémophile comme moi, mais il faisait des choses très étonnantes. Il était consul général pour le Costa Rica — c'était pour moi très mystérieux — et il voyageait constamment autour du globe. Il avait un immense bureau au dernier étage du plus haut édifice de Montréal — encore plus impressionnant — où je me rendais à l'occasion. (Je sais maintenant qu'il était analyste en placements à l'Imperial Trust.) Pour couronner le tout, ô merveille suprême, il possédait des billets de saison pour assister aux parties de hockey du Canadien de Montréal et, lorsque j'étais béni par la chance, il m'invitait à l'accompagner. En regardant la partie, nous parlions de choses et d'autres, y compris de l'hémophilie. C'est en faisant des recherches pour cet article que je suis tombé sur ces paroles prononcées par Frank dans les années 1960.

> *« Je voulais être comme tout le monde. Je ne voulais pas être différent. Alors je n'ai jamais révélé à personne la nature de mon problème. Puis j'ai réalisé que si tous les autres hémophiles faisaient comme moi, comment pouvions-nous espérer faire des progrès ? J'ai senti que nous devions renseigner les gens à propos de l'hémophilie puis travailler, travailler et travailler encore de toutes nos forces pour obtenir de meilleurs traitements, et des possibilités de carrière plus nombreuses. Alors je suis allé à l'autre extrême, et j'ai refusé d'arrêter de parler de l'hémophilie. »*

many more countries to our city for one of the first World Congresses. Imagine how proud Frank would be today to see the number of WFH National Member Organizations surpass one hundred!

As I grew up, Frank's youthful face, with the dark horn-rimmed glasses, was the face of hemophilia. It looked out at me from newspaper and magazine articles which my mother carefully preserved in scrapbooks. Words like these influenced my parents and parents around the world in rearing children with hemophilia.



VICTIM of hemophilia, Montreal's Frank Schnabel shows in a chart, how Queen Victoria passed disease to royal descendants.

TRANSFUSIONS may be needed to stop baby from bleeding to death after even minor childish bumps.

Canadian scientists battle the baffling 'bleeding disease', hemophilia

by ROBERT LITTELL

> *"My parents decided that they didn't want me to live a cotton wool existence and they did everything possible to allow me a normal childhood. My mother later told me it was the hardest thing she ever had to do — to stand back and let me do all the things kids normally do — and then rush me to hospital when I got hurt."*

In these newspaper and magazine photographs, Frank was often flanked by prominent physicians in hemophilia care. Such collaboration was unheard of at the time. Chris Tsoukas, Frank's Montreal physician, once said:

> *"Frank was the one who dared break into the medical establishment and propose a meeting of minds, a cooperation between the care givers and the care receivers. He was the one who by organizing and bringing together hemophiliacs made them feel they were not alone."*

Frank's contribution was more than that of a patient advocate. He became as competent on hemophilia issues as any of the trained medical personnel. Again, in the words of Chris Tsoukas.

> *"Professionally, he was invaluable to me, in helping me begin my research career. He was my sounding board, the person I knew I could talk freely and openly with. He was a great listener and always gave me good advice and encouragement. He helped me to keep my enthusiasm for my work, even during times of gloom."*

Frank's work was recognized outside the hemophilia community. Among many other decorations, he was awarded in 1967 the Centennial Medal by the Government of Canada. In 1970 the International Society for the Rehabilitation of the Disabled designated Frank 'Representative to the Assembly' in recognition of distinguished service rendered to advance the welfare of disabled persons throughout the world.

It is without doubt that Frank's most important achievements were on the world stage. One observer commented, "To most people the world is a big place to live in; to Frank Schnabel, the world was his backyard. He used the

Je me souviens de la fierté de mes parents au sujet de ce jeune Montréalais qui avait réussi à réunir des patients, des parents et des médecins pour fonder la Société canadienne de l'hémophilie en 1953, et qui avait fondé la Fédération mondiale de l'hémophilie 10 ans plus tard, avec, à l'époque, six pays membres — l'Argentine, l'Australie, la Belgique, le Canada, la France et le Royaume-Uni. Et, seulement cinq ans plus tard, il avait amené des représentants de nombreux autres pays dans notre ville, à l'occasion du premier congrès mondial. Imaginez combien Frank serait fier aujourd'hui de voir que le nombre d'organisations membres de la FMH dépasse la centaine !

Alors que je grandissais, le jeune visage de Frank, avec ses lunettes foncées, en écailles, était pour moi le visage de l'hémophilie. Ce visage me regardait depuis les photos dans les magazines et les journaux, accompagnant les articles que ma mère découpait et conservait soigneusement dans un cartable. Des paroles comme celles-ci ont influencé mes parents, tout comme des milliers d'autres autour du globe chargés d'élever un enfant hémophile.

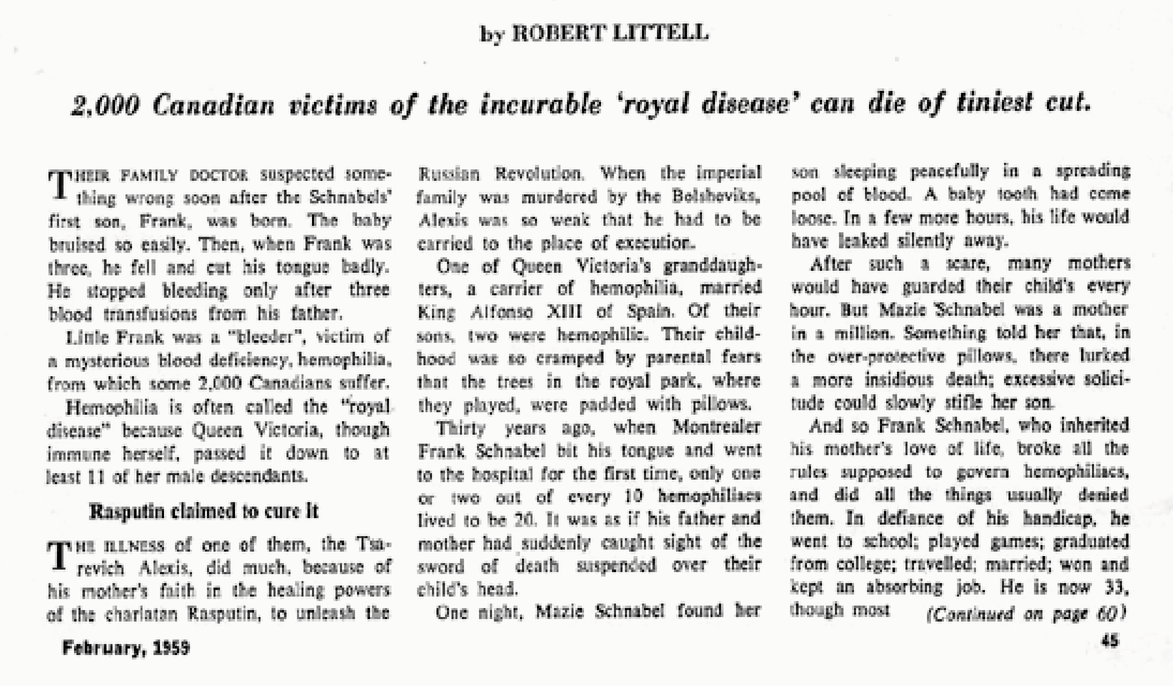
> *« Mes parents ont décidé qu'ils ne voulaient pas que je vive dans un cocon, et ils ont fait l'impossible pour m'offrir une enfance normale. Ma mère m'a dit qu'il s'agissait de la chose la plus difficile qu'elle ait jamais eu à faire — me laisser aller pour que je fasse ce que les autres enfants faisaient — et puis se précipiter avec moi à l'hôpital lorsque je me blessais. »*

Sur ces photos dans les magazines et les journaux, Frank était souvent accompagné d'éminents médecins spécialisés dans le traitement de l'hémophilie. Ce type de collaboration était tout à fait inusité à l'époque. Chris Tsoukas, le médecin montréalais de Frank, a déclaré un jour :

> *« Frank était celui qui osait bousculer l'establishment médical et proposer une rencontre des esprits, une collaboration entre les soignants et les soignés. En réunissant les hémophiles pour qu'ils conjuguent leurs forces, il leur donnait le sentiment profond qu'ils n'étaient plus seuls. »*

L'apport de Frank dépassait celui d'un patient défenseur. Il est devenu aussi compétent sur les questions liées à l'hémophilie que n'importe quel professionnel médical. Voici de nouveau les paroles de Chris Tsoukas.

> *« Sur le plan professionnel, le soutien qu'il m'a accordé pour commencer ma carrière de chercheur en a fait pour moi un être irremplaçable. Son avis m'était extrêmement précieux, il était celui avec qui je savais que je pouvais m'entretenir à cœur ouvert, en toute sincérité. Il écoutait comme personne, et me donnait toujours de bons conseils et des encouragements. Il m'a aidé à conserver mon enthousiasme envers mon travail, même dans les temps difficiles. »*



by ROBERT LITTELL

2,000 Canadian victims of the incurable 'royal disease' can die of tiniest cut.

THEIR FAMILY DOCTOR suspected something wrong soon after the Schnabels' first son, Frank, was born. The baby bruised so easily. Then, when Frank was three, he fell and cut his tongue badly. He stopped bleeding only after three blood transfusions from his father.

Little Frank was a "bleeder", victim of a mysterious blood deficiency, hemophilia, from which some 2,000 Canadians suffer.

Hemophilia is often called the "royal disease" because Queen Victoria, though immune herself, passed it down to at least 11 of her male descendants.

Rasputin claimed to cure it

THE ILLNESS of one of them, the Tsarevich Alexis, did much, because of his mother's faith in the healing powers of the charlatan Rasputin, to unleash the Russian Revolution. When the imperial family was murdered by the Bolsheviks, Alexis was so weak that he had to be carried to the place of execution.

One of Queen Victoria's granddaughters, a carrier of hemophilia, married King Alfonso XIII of Spain. Of their sons, two were hemophilic. Their childhood was so cramped by parental fears that the trees in the royal park, where they played, were padded with pillows.

Thirty years ago, when Montrealer Frank Schnabel bit his tongue and went to the hospital for the first time, only one or two out of every 10 hemophiliacs lived to be 20. It was as if his father and mother had suddenly caught sight of the sword of death suspended over their child's head.

One night, Mazie Schnabel found her son sleeping peacefully in a spreading pool of blood. A baby tooth had come loose. In a few more hours, his life would have leaked silently away.

After such a scare, many mothers would have guarded their child's every hour. But Mazie Schnabel was a mother in a million. Something told her that, in the over-protective pillows, there lurked a more insidious death; excessive solicitude could slowly stifle her son.

And so Frank Schnabel, who inherited his mother's love of life, broke all the rules supposed to govern hemophiliacs, and did all the things usually denied them. In defiance of his handicap, he went to school; played games; graduated from college; travelled; married; won and kept an absorbing job. He is now 33, though most

(Continued on page 60)

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newspapers, telex and the telephone to shrink the world to manageable size." Imagine what he would have accomplished in the era of E-mail and Internet!

Frank's extensive travel on behalf of WFH could not have been without sacrifice. The Reverend Alan Tanner, former Chairman of the WFH, said of Frank:

> *"I think he must have been one of the most widely traveled people ever. And on all those occasions I have seen his single minded devotion to the national member organizations and to individuals who came to him for advice and guidance. He was the pioneer in establishing this great blood brotherhood. And all of this was achieved at great personal cost to himself, because he never spared himself. Lesser men would not have started the journey."*

I happened to be in hospital in Montreal at the same time as Frank just before his death in 1987 at the age of 61. His hospital room had become the nerve centre of the WFH. Frank was summoning people to his bedside so that his work could continue. Few of us could tell how ill he was. Only weeks later, The Reverend Tanner spoke these words in Frank's eulogy.

> *"For many years to come, the names of the World Federation of Hemophilia and Frank Schnabel will be synonymous; and many boys and men throughout the world look to Frank Schnabel as their model and their hero because he demonstrated so clearly that they could rise above the complications of hemophilia and turn adversity into triumph."*

This tribute to Frank Schnabel first appeared in the March 2003 issue of Haemophilia World, on the occasion of the 40th anniversary of the World Federation of Hemophilia.

L'apport de Frank était reconnu au-delà de la communauté de l'hémophilie. Entre autres honneurs, il a reçu la Médaille du Centenaire du gouvernement du Canada en 1967. En 1970, Réhabilitation internationale a décerné à Frank le titre de « représentant de l'assemblée », en reconnaissance de services distingués rendus pour favoriser le bien-être, des personnes ayant une déficience à l'échelle du globe.

Sans nul doute, les réalisations les plus importantes de Frank ont eu lieu sur la scène mondiale. Un observateur déclarait : « Pour la plupart des gens, le monde est un immense espace à habiter ; pour Frank Schnabel, le monde était sa cour arrière. Il se servait des journaux, du télex et du téléphone pour réduire le monde à un environnement gérable. » Imaginez seulement ce qu'il aurait pu faire à l'ère du courriel et d'Internet !

Les nombreux déplacements de Frank au nom de la FMH n'ont pu se faire sans sacrifices. Le révérend Alan Tanner, ancien président de la FMH, a dit de Frank :

> *« Je crois qu'il a été l'un des plus grands voyageurs de tous les temps. À tout moment, j'ai été témoin de son entière dévotion envers les organisations nationales et les personnes qui le consultaient pour obtenir des conseils. Il a été le pionnier qui a créé la grande fraternité du sang. Il a réalisé tout cela au détriment de sa santé, parce qu'il ne se ménageait pas. Des hommes de moindre valeur ne se seraient jamais lancés dans une pareille aventure. »*

J'étais hospitalisé à Montréal en même temps que Frank, juste avant sa mort, en 1987, à l'âge de 61 ans. Sa chambre était devenue le quartier général de la FMH. Frank convoquait les gens à son chevet, afin que son œuvre se poursuive. Peu d'entre nous pouvaient dire à quel point il était malade. Quelques semaines plus tard, le révérend Tanner rendait ainsi hommage à Frank dans son éloge funèbre.

> *« Pendant encore de nombreuses années, Fédération mondiale de l'hémophilie et Frank Schnabel seront synonymes ; et nombreux sont les garçons et les hommes pour lesquels Frank Schnabel est un modèle et un héros, parce qu'il a fait la preuve hors de tout doute qu'ils pouvaient transcender les complications de l'hémophilie, et transformer l'adversité en triomphe. »*

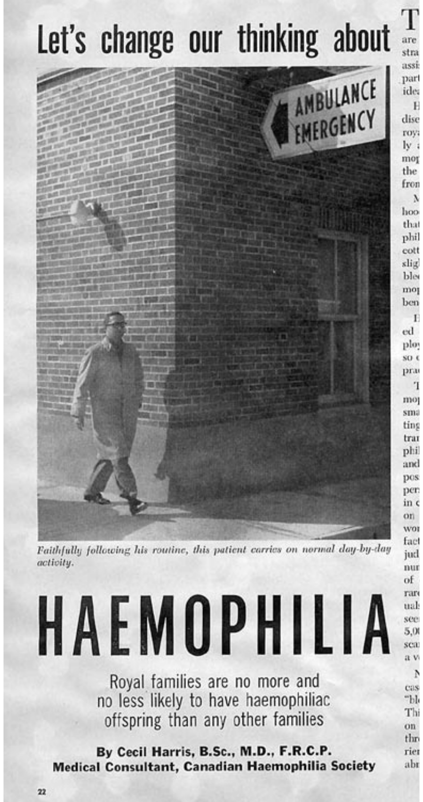
Cet hommage à Frank Schnabel a d'abord été publié dans le numéro de mars 2003 de *Haemophilia World*, à l'occasion du 40^{e} anniversaire de la Fédération mondiale de l'hémophilie.

Cecil E.C. Harris, MD

Dr. Harris trained as a physician in Great Britain. He moved to Montreal in the early 1950s where he began to practise hematology at St. Mary's Hospital. One of his first patients was Frank Schnabel, who went on to found the CHS. The two men forged a powerful alliance to push for better care for hemophiliacs. Dr. Harris set up the first adult hemophilia centre in Montreal at St. Mary's in 1955. From the outset, Dr. Harris was at the centre of CHS activities, as the first medical consultant for the organization and serving many years on the Medical and Scientific Advisory Board. In fact, he was so involved that his wife, Pat, decided to volunteer her time and was CHS President from 1972 to 1975.

Dr. Harris ran the St. Mary's hemophilia clinic for more than 25 years and was forced to stop only when the hospital administration objected to his visionary approach to the treatment of bleeding and pain in hemophilia. All his patients remember him as a strong advocate on their behalves. When a patient went to see him, no matter what shape he was in, he couldn't get out of Dr. Harris' presence without hearing his joke of the day, told with a wry British sense of humour.

Dr. Harris was one of the world's leading specialists in hemophilia care in the 1950s, 60s and 70s and, no matter where you go today in the international hemophilia community, Dr. Harris is remembered and admired.



Let's change our thinking about

Faithfully following his routine, this patient carries on normal day-by-day activity.

HAEMOPHILIA

Royal families are no more and no less likely to have haemophiliac offspring than any other families

By Cecil Harris, B.Sc., M.D., F.R.C.P.
Medical Consultant, Canadian Haemophilia Society

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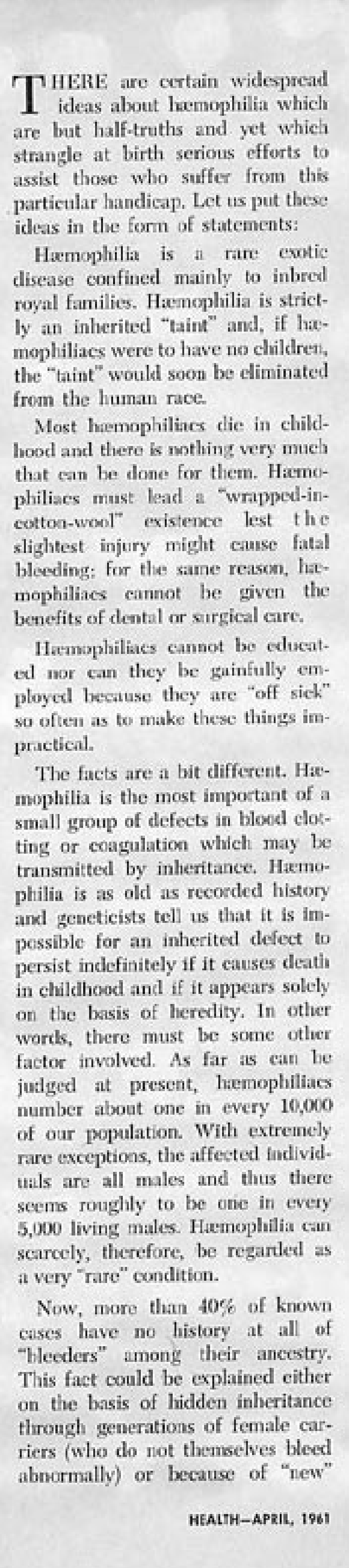


There are certain widespread ideas about hæmophilia which are but half-truths and yet which strangle at birth serious efforts to assist those who suffer from this particular handicap. Let us put these ideas in the form of statements:

Hæmophilia is a rare exotic disease confined mainly to inbred royal families. Hæmophilia is strictly an inherited "taint" and, if hæmophiliacs were to have no children, the "taint" would soon be eliminated from the human race.

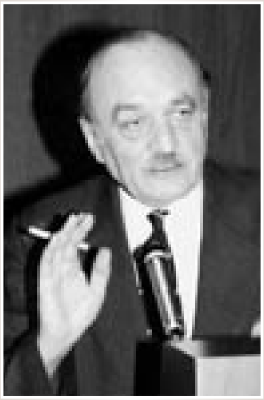
Most hæmophiliacs die in childhood and there is nothing very much that can be done for them. Hæmophiliacs must lead a "wrapped-in-cotton-wool" existence lest the slightest injury might cause fatal bleeding; for the same reason, hæmophiliacs cannot be given the benefits of dental or surgical care.

Hæmophiliacs cannot be educated nor can they be gainfully employed because they are "off sick" so often as to make these things impractical.

The facts are a bit different. Hæmophilia is the most important of a small group of defects in blood clotting or coagulation which may be transmitted by inheritance. Hæmophilia is as old as recorded history and geneticists tell us that it is impossible for an inherited defect to persist indefinitely if it causes death in childhood and if it appears solely on the basis of heredity. In other words, there must be some other factor involved. As far as can be judged at present, hæmophiliacs number about one in every 10,000 of our population. With extremely rare exceptions, the affected individuals are all males and thus there seems roughly to be one in every 5,000 living males. Hæmophilia can scarcely, therefore, be regarded as a very "rare" condition.

Now, more than 40% of known cases have no history at all of "bleeders" among their ancestry. This fact could be explained either on the basis of hidden inheritance through generations of female carriers (who do not themselves bleed abnormally) or because of "new"

HEALTH—APRIL, 1961



Le Dr Harris a obtenu son diplôme de médecine en Grande-Bretagne. Il a déménagé à Montréal au début des années 1950, où il a commencé à pratiquer comme hématologue à l'Hôpital St. Mary's. Un de ses premiers patients a été Frank Schnabel, le fondateur de la SCH. Les deux hommes ont formé une solide alliance pour se battre afin d'obtenir de meilleurs soins pour les hémophiles. C'est à St. Mary's que le Dr Harris a fondé le premier centre de l'hémophilie pour adultes à Montréal en 1955. À partir du début, le Dr Harris a été au centre des activités de la SCH, en tant que premier conseiller médical de l'organisation, et membre du comité consultatif médical et scientifique pendant de nombreuses années. En fait, son engagement était si grand qu'il était contagieux : son épouse, Pat, a joint elle aussi les rangs des bénévoles et a été présidente de la SCH de 1972 à 1975.

Le Dr Harris a dirigé la clinique de l'hémophilie de St. Mary's pendant plus de 25 ans, il a été forcé d'abandonner lorsque l'administration de l'hôpital s'est opposée à son approche visionnaire du traitement des saignements et de la douleur chez les hémophiles. Tous ses patients s'en souviennent comme d'un ardent défenseur de leurs intérêts. Lorsqu'un patient venait le consulter, peu importe sa condition physique, il ne pouvait quitter le bureau du Dr Harris sans avoir entendu la blague du jour, racontée avec un sens de l'humour typiquement britannique.

Le Dr Harris a été l'un des leaders mondiaux en matière de soins de l'hémophilie au cours des années 50, 60 et 70. Aujourd'hui, peu importe où vous vous rendez dans la communauté hémophile internationale, on se souvient du Dr Harris avec une grande admiration.

David Page

MY LASTING MEMORY IS THE MANY, MANY PAINFUL DAYS AND NIGHTS

Enid Page, *Montreal*

The history of the CHS started in 1953 and our son David's medical history with factor IX deficiency hemophilia began then also.

The next ten years were learning years for us and for the doctors. We were so very privileged to have two wonderful mentors in Montreal in Doctors Ronald Denton and Robert Gourdeau, hematologists, and Doctor Shugar, an orthopedic surgeon. Once, I remember Dr. Gourdeau staying up all night to put pressure on a bleeding elbow.

In those early days, whole blood and fresh frozen plasma were the only available treatments to stop the bleeding. Sometimes, the I.V. remained in David's arm for five or six days, continuously, and when the bleed was in a joint — knee, elbow or ankle — it was 'aspirated' to draw out the fluid which was causing the swelling and severe pain. I remember the many, many painful days and nights he suffered as a result of these hemorrhages. A plaster cast was usually applied to immobilize the joint. It was kept on for two or three weeks until the bleeding had stopped. We played many games of Snakes and Ladders, Snap, Old Maid, Checkers, I Spy, chess and cribbage. We read a lot, too! When the cast was removed, physiotherapy was gently started to get the joint back to mobility again There was a very fine line between too little and too much activity during that time.

David missed an average of seventy-five days of school per year but he kept up with his school work very well. We lived across the street from the school, so, quite often, I took him there on his wagon or walked with him on his crutches. The teachers were very kind and helpful — even carrying him out of the school during a fire-drill!

Enid and Douglas Page, founding members of the CHS in 1953. Doug also served as the first president of the Quebec Chapter, from 1959 to 1966.

Enid et Douglas Page, membres fondateurs de la SCH en 1953. Douglas a également été le premier président de la Section Québec, de 1959 à 1966.

For my own curiosity, I kept a diary of David's admissions, and now I find it a very interesting document. During the period 1953-1963, he was admitted to hospital a total of 88 times — sometimes for a week, sometimes for six weeks, though a six-week stay was rare. The largest number of admissions was during the period January 1961 to January 1962 — eighteen times in that one year. So I guess age 9 - 10 is the hardest on an active boy.

The hospital never suggested home care or self infusion. It wasn't even considered in those days. Therefore, we were at the mercy of young interns who seemed to be learning to do transfusions for the first time. We had a new one every time. So inept were they that they sometimes poked eight or nine times before they hit the vein, thus wrecking the site for future needs.

And, these interns didn't want Mom to be in the room! I was sent out into the hall while the procedure went on and on! But later, when they got to know me a bit better (and I became more assertive), I was allowed to stay… if I promised not to interfere. It was very hard on all of us; the intern becoming more and more frustrated and David and I more and more upset.

UN SOUVENIR INEFFAÇABLE : DES JOURNÉES ET DES NUITS REMPLIES DE DOULEUR

L'histoire de la SCH débute en 1953, tout comme celle de l'hémophilie (déficience du facteur IX) de notre fils David.

La décennie qui suivit fut une période d'apprentissage pour nous et pour les médecins. Nous avons été privilégiés de trouver sur notre route, à Montréal, les deux merveilleux mentors qu'ont été les hématologues Ronald Denton et Robert Gourdeau, ainsi que le Dr Shugar, chirurgien orthopédique. Toute une nuit durant, le Dr Gourdeau a appliqué de la pression sur le coude de mon fils, qui ne cessait de saigner.

À l'époque, pour arrêter une hémorragie, il fallait du sang total et du plasma congelé. David gardait parfois l'intraveineuse dans le bras pendant cinq ou six jours, en permanence. Et quand il s'agissait d'une hémorragie dans une articulation – genou, coude ou cheville –, on « aspirait » pour dégager le liquide qui causait l'enflure et la douleur aiguë. Je me souviens des jours et des nuits de souffrance, qui se succédaient sans relâche. Pour immobiliser l'articulation, on lui faisait habituellement un plâtre, qu'il gardait deux ou trois semaines, jusqu'à l'arrêt de l'hémorragie. Nous avons joué d'incalculables parties de serpents et échelles, de dames, d'échecs, de cribbage. Et nous avons lu ! Une fois le plâtre retiré, David faisait de la physiothérapie pour doucement remettre l'articulation en mouvement. Il n'était pas facile de tracer la ligne entre trop et trop peu d'activité.

Notre fils manquait en moyenne 75 jours d'école par année, mais ses résultats scolaires étaient excellents. Notre maison se trouvait en face de l'école et, bien souvent, j'allais le conduire dans son petit chariot ou il s'y rendait à l'aide de béquilles. Ses enseignants, aimables et serviables, l'ont même porté à l'extérieur pendant un exercice d'incendie !

Par curiosité, je notais dans un journal ses séjours à l'hôpital. Ce document est très intéressant : de 1953 à 1963, David a été hospitalisé 88 fois ; les séjours pouvaient durer une semaine, parfois six, mais plus rarement. Entre janvier 1961 et janvier 1962, les hospitalisations ont atteint un sommet : 18 en une seule année. J'en ai conclu que la période la plus éprouvante pour un garçon actif devait se situer vers l'âge de 9 ou 10 ans.

À l'hôpital, il n'a jamais été question de soins à domicile ou d'autoperfusion. On n'y pensait même pas à l'époque. Nous étions à la merci de jeunes internes qui, semble-t-il, s'initiaient aux transfusions. Peu doués, ils devaient s'y reprendre à huit ou neuf fois avant de trouver la veine, rendant la région inutilisable pour des besoins futurs. Et, chaque fois, on avait affaire à un nouvel interne.

Les internes ne voulaient surtout pas de maman dans la pièce ! On m'envoyait dans le couloir pendant l'interven-

We spent vacations at the family cottage in New Brunswick. I can remember his grandmother painstakingly picking up every clam shell from the beach in front of our cottage, so David wouldn't cut his feet on them.

Quite early in the life of the CHS, we became recruiters for blood donations. We planned and helped run clinics and we worked hard to raise money for the Society. We held card parties in church basements and my husband sold boxes of Christmas cards. One year he made $40.00!

These were interesting times, and scary as well. My lasting memory is the many, many painful days and nights and all the times he was away from home, friends and school.

We feel great pride in what the CHS has become today.

Congratulations on 50 years of service
to people with hemophilia
and other inherited bleeding disorders

From **David Page and Patricia Stewart**

And from **Enid and Douglas Page**,
proud to have been part of
the founding of the CHS in 1953

tion… qui me paraissait interminable. Avec le temps, ils ont appris à mieux me connaître (et moi à m'affirmer). On m'a permis de rester dans la chambre, pourvu que je n'intervienne pas. C'était pénible pour tout le monde ; l'interne se sentait de plus en plus frustré, et David et moi avions de plus en plus de difficulté à garder notre calme.

Nous passions nos vacances dans le chalet familial, au Nouveau-Brunswick. Je revois la grand-mère de David ramasser minutieusement tous les coquillages de la plage devant la maison, pour éviter que David ne se coupe les pieds.

Assez tôt après la fondation de la SCH, mon mari et moi avons commencé à faire du recrutement pour les collectes de sang. Nous avons organisé des cliniques de sang, participé aux activités et travaillé d'arrache-pied pour recueillir des fonds. Sans parler des parties de cartes organisées dans les sous-sols d'église et des cartes de Noël vendues par mon mari. Une année, ses ventes ont totalisé 40 $!

C'était une époque stimulante mais angoissante. Mon souvenir le plus tenace, c'est la douleur, des jours et des nuits durant. Et tout ce temps que David a passé loin de la maison, de ses amis et de l'école.

Les réalisations de la Société nous remplissent d'une immense fierté !

JOYCE ROSENTHAL

The Ontario Chapter was founded at a meeting of a group of concerned parents and hemophiliacs in the Rosenthal home in 1957, with Joyce Rosenthal as its first President from 1957 to 1965. During her presidency and in collaboration with her educator-sister, Lois Bedard, the chapter distinguished itself in areas of education and public advocacy. In 1958 the first edition of *The Report* was published in Toronto, destined to become the national publication *Hemophilia Today*. Pamphlets were published on "Dental Care for the Hemophiliac", "Home Care of the Hemophilia Child", and "The Hemophiliac in School", and distributed nationally. Joyce and Lois made submissions to the Royal Commission on Health Services in 1962 proposing "totality of treatment" for hemophiliacs, the forerunner of what we now know as comprehensive care. A public submission was also made on socio-vocational adaptation of young hemophiliacs; position papers were developed on birth control, voluntary legalized sterilization, and voluntary legalized abortion. By 1963 auxiliaries (now known as regions) were established in Ontario.

Joyce Rosenthal and Lois Bedard, two sisters who played a key role in the early years of the CHS and its Ontario Chapter

Joyce Rosenthal et Lois Bedard, deux sœurs qui ont joué un rôle clé au cours des premières années d'existence de la SCH et de sa Section Ontario.

La section de l'Ontario a été fondée chez les Rosenthal en 1957, lors d'une réunion d'un groupe de parents et d'hémophiles inquiets ; Joyce Rosenthal a été la première présidente de cette section, de 1957 à 1965. Au cours de son mandat, en collaboration avec sa sœur enseignante, Lois Bedard, la section s'est distinguée dans des secteurs comme l'éducation et la défense d'intérêts publics. En 1958, la première édition de *The Report* paraît à Toronto, ce qui devait devenir plus tard la publication nationale *L'hémophilie de nos jours*. Des dépliants au sujet des soins dentaires à l'intention des hémophiles, des soins à domiciles pour les enfants atteints d'hémophilie ainsi que sur l'enfant hémophile à l'école ont été publiés, et distribués à l'échelle nationale. Joyce et Lois ont fait, en 1962, une proposition de « traitement total » pour les hémophiles à la Commission royale sur les services de santé, ce qui devait ouvrir la voie à ce que nous appelons aujourd'hui les soins complets. Une proposition publique a également été faite au sujet de l'adaptation socioprofessionnelle des jeunes hémophiles ; des articles prenant

In 1965, Joyce Rosenthal was hired as National Executive Secretary (with a shared responsibilty for both the national and Ontario organizations) of the Canadian Hemophilia Society, with her office being located in Toronto under the auspices of the Canadian Rehabilitation Council for the Disabled. One of the most significant contributions made during her four-year tenure was a tour of Maritime and western Canadian hemophilia chapters and unorganized groups, advising fledgling chapters and stimulating the creation of new ones where they didn't exist.

From 1970 Joyce served for two years as the Chair of the newly-established Toronto Auxiliary. In those years of building, the major thrusts were introduction of a newsletter, increased attention to fundraising (including the gala opening of the movie Nicholas and Alexandra), and establishment of a joint office with the Ontario Chapter.

Joyce Rosenthal's contributions were recognized by the Government of Canada who conferred the Centennial Medal in 1967. In 1972 she was made an Honourary Life Member of the Canadian Hemophilia Society. She and Lois Bedard were similarly recognized by Hemophilia Ontario. In 2000 the two sisters (who were always so much a team) received the Chapter Leadership Award from the CHS.

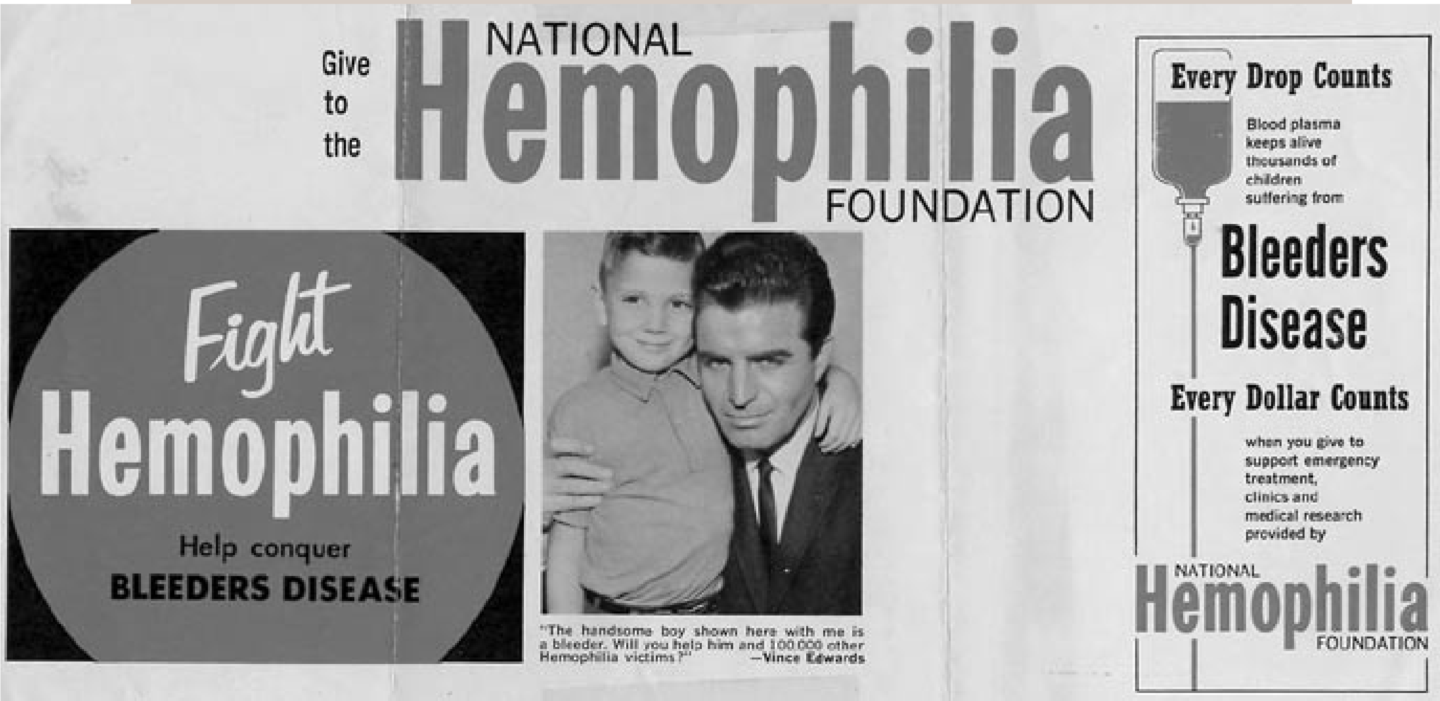
Frank Bott

position sur le contrôle des naissances, ainsi que sur la stérilisation et l'avortement légaux volontaires ont été publiés. Dès 1963, des groupes régionaux avaient été constitués en Ontario.

En 1965, Joyce Rosenthal a obtenu le poste de secrétaire exécutive nationale (avec une responsabilité envers l'organisation nationale et celle de l'Ontario) à la Société canadienne de l'hémophilie, avec un bureau situé à Toronto sous les auspices du Conseil National des Timbres de Pâques et de la Parade des Dix Sous. L'une des contributions les plus importantes de son mandat de quatre ans a été une tournée d'un bout à l'autre du pays, des Maritimes jusqu'aux Rocheuses, afin de prodiguer conseils et encouragement aux sections existantes, et de stimuler la création de nouvelles sections auprès de groupes non structurés.

À partir de 1970, Joyce a été présidente du nouveau groupe auxiliaire de Toronto. Au cours de ces années de construction, elle a orienté ses efforts vers la création d'un bulletin, l'amélioration de l'efficacité de la collecte de fonds (notamment le gala d'ouverture du film Nicolas et Alexandra), et la mise sur pied d'un bureau conjoint avec la section ontarienne.

Les réalisations de Joyce Rosenthal ont été reconnues par le gouvernement du Canada, qui lui a décerné la récompense du centenaire en 1967. En 1972, elle a été nommée membre honoraire à vie de la Société canadienne de l'hémophilie. Elle et Lois Bedard ont reçu une reconnaissance similaire de la part d'Hémophilie Ontario. En 2000, la SCH a décerné aux deux sœurs (une formidable équipe de toujours) la récompense pour leadership provincial.



In the first years after its founding, the CHS was actually a chapter of the U.S. National Hemophilia Foundation.

Au cours de ses premières années d'existence, la SCH était une section de la National Hemophilia Foundation des États-Unis.

Appendectomy Makes History

By LARRY POITRAS

Medicine reached another milestone today as Montreal Children's Hospital doctors announced that they had carried out what is believed to be the first successful appendectomy operation on a haemophilia patient in North America.

Nine-year-old Donald Burns of 2585 Cirier street in Montreal's east end Champlain district, is back home today after receiving bottle upon bottle of specially treated plasma transfusions in a last-resort operation for acute appendicitis.

Frank Schnabel, president of the Canadian Haemophilia Society told The Star today: "To my knowledge, no other haemophiliac has submitted to an appendectomy in this part of the continent. In fact, every measure has been attempted in the past to avoid operating in such cases," he said.

Strange Disease'

Haemophilia is described by experts as a strange disease the effect of which is to retard blood coagulation for as long as one or two hours.

The bleeding disorder is transmitted from generation to generation through the female line. However, though mothers are its carriers, males alone are its sufferers.

Donald's older brother, Edward, who turned 12 last week, also is a haemophiliac. Recurrent damages to the child's leg joints, brought about by the disease, have resulted in Edward having to wear braces.

"However we have been informed that Edward's braces will soon be removed," his father, Gordon Burns, who is assistant foreman at National Liquids Company, proudly reported.

Donald, who has shown only slight signs of weakness following the operation, has never required braces to walk with.

Although special care had to be taken to prevent his children from suffering external and internal bleeding, Mr. Burns said his family had submitted itself to facing the task. "And the children have accepted their somewhat sheltered lives without complaining."

Mr. Burns described as taboo such games as hockey, football and baseball.

Mrs. Burns praised the Montreal Children's Hospital and the School for Crippled Children for the attention their children had received.

"We're just one of a number of families that have to face this problem," she said.

Mrs. Burns, whose 13-year-old daughter, Carol, shows no sign of the disease, said two of her aunts, now living in New York, were carriers of haemophilia. "Carol herself may very well be a carrier," she added.

'Royal Disease'

Haemophilia has long been labelled the "royal disease." Queen Victoria was a carrier and so were three of her daughters and four of her granddaughters.

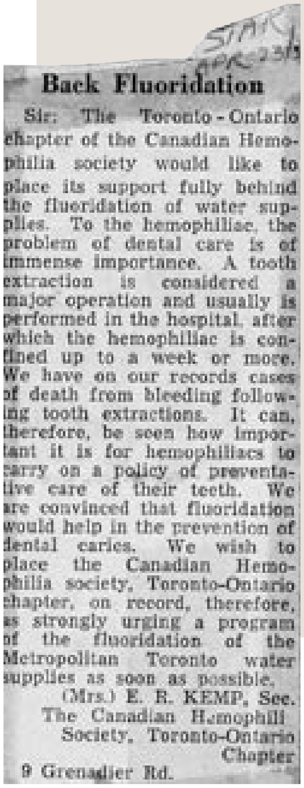
One of her granddaughters, the Queen of Spain, is believed to have transmitted the disorder to the Spanish royal family. Her son, the Count of Covadonga, bled to death following an automobile accident at Miami.

Alexis, the son of Nicholas II, Russia's last Czar, who was assassinated with his entire family by the Bolsheviks in 1918, was also a haemophiliac. The disease also has been reported in the Hapsburg royal family of Austria.

Mr. Schnabel said that, contrary to public opinion, the disease's most serious aspects were in the form of internal haemorrhages which, after constant gnawing at bones and joints, often resulted in haemophiliac arthritis.

He added [illegible] although most cases were transmitted from mother to son, about 40 per cent of the cases arose in families without previous history in the bleeding disorder.

Nine-year-old Donald Burns smiles on father's knee. His is believed to be first successful appendectomy operation to a haemophiliac in North America.



STAR
APR 23/5

Back Fluoridation

Sir: The Toronto-Ontario chapter of the Canadian Hemophilia society would like to place its support fully behind the fluoridation of water supplies. To the hemophiliac, the problem of dental care is of immense importance. A tooth extraction is considered a major operation and usually is performed in the hospital, after which the hemophiliac is confined up to a week or more. We have on our records cases of death from bleeding following tooth extractions. It can, therefore, be seen how important it is for hemophiliacs to carry on a policy of preventative care of their teeth. We are convinced that fluoridation would help in the prevention of dental caries. We wish to place the Canadian Hemophilia society, Toronto-Ontario chapter, on record, therefore, as strongly urging a program of the fluoridation of the Metropolitan Toronto water supplies as soon as possible.

(Mrs.) E. R. KEMP, Sec.
The Canadian Hemophili
Society, Toronto-Ontario
Chapter
9 Grenadier Rd.

"Bill" Rudd, Local Boy, First To Receive New Type Blood Transfusion

THE LIBERAL MAR 24/60

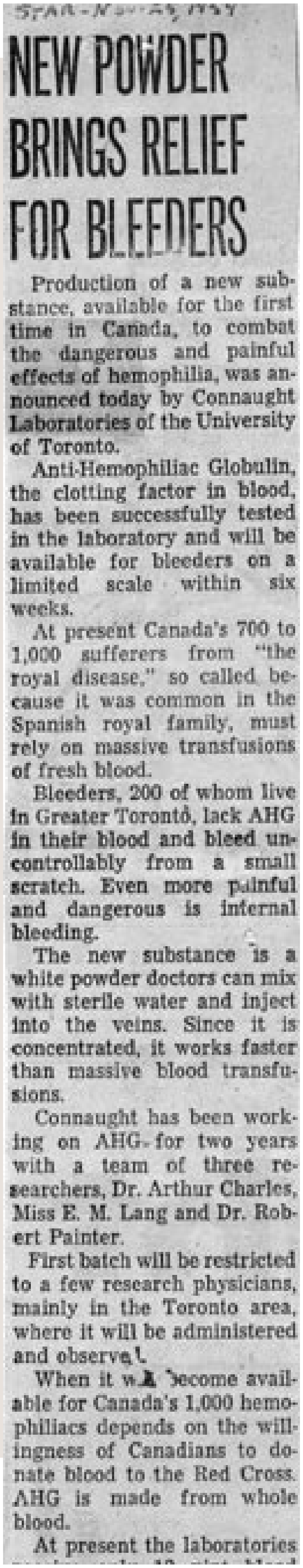
Young R. W. ("Bill") Rudd of Richmond Hill — contributed to the success of an amazing test conducted in Toronto General Hospital — one that marks a record advance in the history of medical blood transfusion. For the first time in Canada on Tuesday of last week, doctors administered to Bill the first new concentrated blood derivative produced by the Connaught Laboratories in cooperation with the Canadian Red Cross.

This new substance is known as "concentrated anti-hemophilic globulin," requiring twelve pints of blood to produce one flask of this new substance, the objective of which is to stop hemorrhages, but the great value of this new blood derivative is the element of time in transfusion, as it speeds up the clotting factor.

Citing this first case: In present blood transfusions, two to

pled joints — to the accompaniment of the worst pain imaginable, or even death. The average victim receives 45 transfusions per year, and it is not unusual for a boy to require two and three transfusions a day for weeks at a time. In some cases, it is the constant recurrence that causes hemophilia to be referred to as "the world's most expensive disease."

Bill Rudd was born in Vancouver, B. C., and is physically able to engage in all normal activities that do not endanger internal conditions. Though ten of his twenty years have been spent in hospitals, it has never retarded his education. Bill commenced his schooling at the age of six, continuing right on, never missing a grade; on graduating from high school, he attended the University of St. John's, Newfoundland, and shortly will resume his



STAR - NOV - 25, 1959

NEW POWDER BRINGS RELIEF FOR BLEEDERS

Production of a new substance, available for the first time in Canada, to combat the dangerous and painful effects of hemophilia, was announced today by Connaught Laboratories of the University of Toronto.

Anti-Hemophiliac Globulin, the clotting factor in blood, has been successfully tested in the laboratory and will be available for bleeders on a limited scale within six weeks.

At present Canada's 700 to 1,000 sufferers from "the royal disease," so called because it was common in the Spanish royal family, must rely on massive transfusions of fresh blood.

Bleeders, 200 of whom live in Greater Toronto, lack AHG in their blood and bleed uncontrollably from a small scratch. Even more painful and dangerous is internal bleeding.

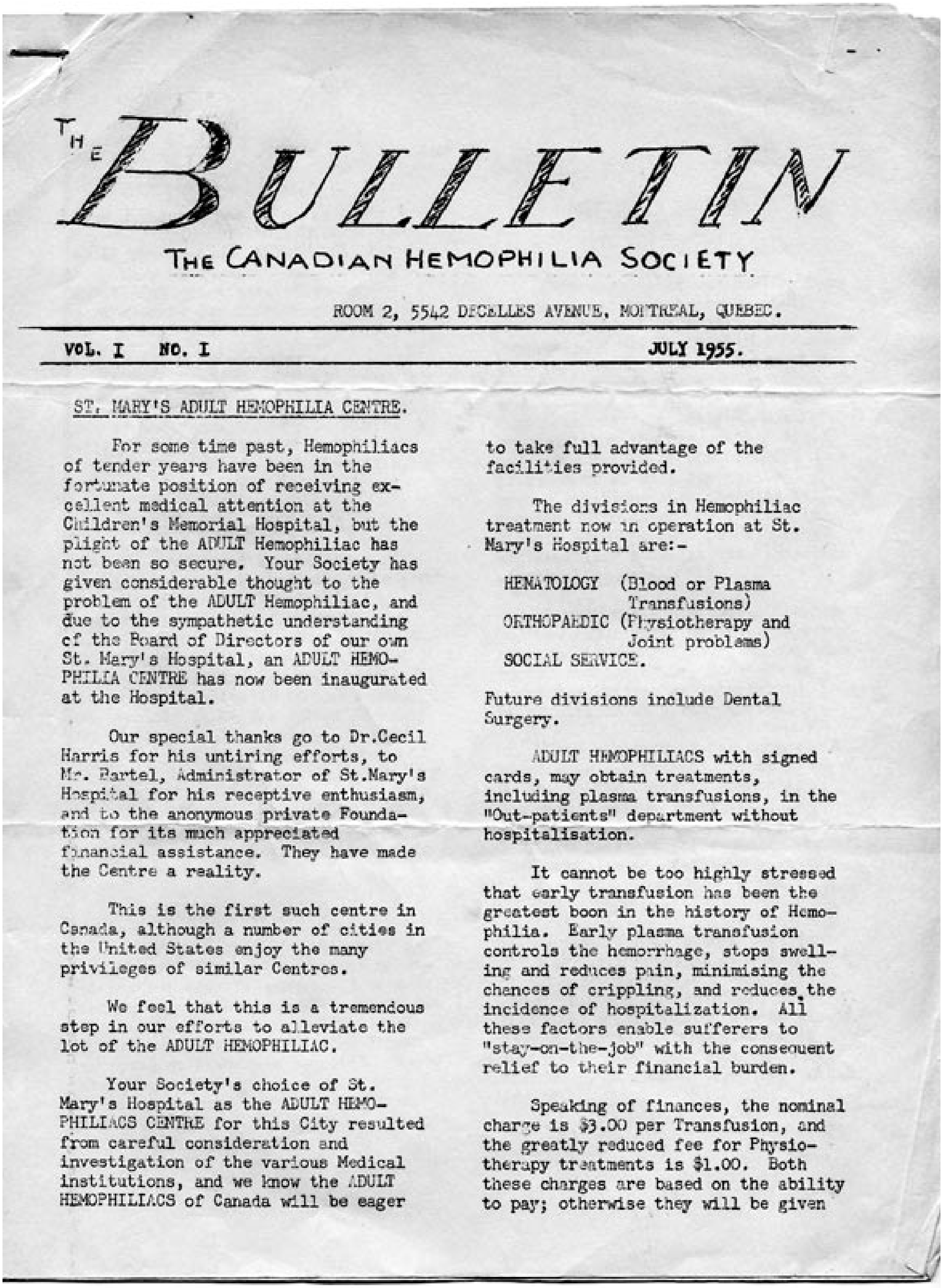
The new substance is a white powder doctors can mix with sterile water and inject into the veins. Since it is concentrated, it works faster than massive blood transfusions.

Connaught has been working on AHG for two years with a team of three researchers, Dr. Arthur Charles, Miss E. M. Lang and Dr. Robert Painter.

First batch will be restricted to a few research physicians, mainly in the Toronto area, where it will be administered and observed.

When it will become available for Canada's 1,000 hemophiliacs depends on the willingness of Canadians to donate blood to the Red Cross. AHG is made from whole blood.

At present the laboratories



THE BULLETIN

THE CANADIAN HEMOPHILIA SOCIETY

ROOM 2, 5542 DECELLES AVENUE, MONTREAL, QUEBEC.

VOL. I NO. I JULY 1955.

ST. MARY'S ADULT HEMOPHILIA CENTRE.

For some time past, Hemophiliacs of tender years have been in the fortunate position of receiving excellent medical attention at the Children's Memorial Hospital, but the plight of the ADULT Hemophiliac has not been so secure. Your Society has given considerable thought to the problem of the ADULT Hemophiliac, and due to the sympathetic understanding of the Board of Directors of our own St. Mary's Hospital, an ADULT HEMOPHILIA CENTRE has now been inaugurated at the Hospital.

Our special thanks go to Dr.Cecil Harris for his untiring efforts, to Mr. Bartel, Administrator of St.Mary's Hospital for his receptive enthusiasm, and to the anonymous private Foundation for its much appreciated financial assistance. They have made the Centre a reality.

This is the first such centre in Canada, although a number of cities in the United States enjoy the many privileges of similar Centres.

We feel that this is a tremendous step in our efforts to alleviate the lot of the ADULT HEMOPHILIAC.

Your Society's choice of St. Mary's Hospital as the ADULT HEMOPHILIACS CENTRE for this City resulted from careful consideration and investigation of the various Medical institutions, and we know the ADULT HEMOPHILIACS of Canada will be eager to take full advantage of the facilities provided.

The divisions in Hemophiliac treatment now in operation at St. Mary's Hospital are:-

HEMATOLOGY (Blood or Plasma Transfusions)
ORTHOPAEDIC (Physiotherapy and Joint problems)
SOCIAL SERVICE.

Future divisions include Dental Surgery.

ADULT HEMOPHILIACS with signed cards, may obtain treatments, including plasma transfusions, in the "Out-patients" department without hospitalisation.

It cannot be too highly stressed that early transfusion has been the greatest boon in the history of Hemophilia. Early plasma transfusion controls the hemorrhage, stops swelling and reduces pain, minimising the chances of crippling, and reduces the incidence of hospitalization. All these factors enable sufferers to "stay-on-the-job" with the consequent relief to their financial burden.

Speaking of finances, the nominal charge is $3.00 per Transfusion, and the greatly reduced fee for Physiotherapy treatments is $1.00. Both these charges are based on the ability to pay; otherwise they will be given

Scrappy Hemophilia Dogs Pose Problem for OVC

By EUGENE MCCARTHY
Record Staff Writer

GUELPH—One day last year, two cairn terrier owners brought their dogs at
Toronto veter
One dog ha
tracted, the
moved. Seve
veterinarian
bleeding unc
points of the
He called
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told to bring
college for e

AFFECTS F

It was aft
examination
animals dep
quent study

hemophiliac dogs opened a new field of research for a physiological sciences research team, the key members of which are Dr. H. G. Downie, Dr. H. C.

but at 5 p.m. and on weekends, the emergencies never fail to arise.

To combat some of their prob-

Kilchener/Waterlo Record Mon Feb. 6/1961

CANINE CONQUEST — Dr. David Secord (left) of the Ontario Veterinary College holds Tuffy, the world's first female dog to have the rare disorder, hemophilia. Dr. H. C. Rowsell (centre) and Mico Divjak of the same department display male beagles who are also afflicted with hemophilia.

Record Photo

Unique Hospital Service

Beds Always Ready For Child Bleeders

By FRED POLAND

Any time of the day or night there is always a bed available in the Montreal Children's Hospital for a patient with hemophilia, the dread, incurable, inherited disease whose victims' blood does not clot properly and who are often in danger of bleeding
This
the hos
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liac it will go on till something is done about it."

In urgent cases, the patient gets fresh blood, followed by fresh frozen plasma, a blood constituent. Sometimes plasma alone will arrest bleeding. Usually it takes three or four bottles.

Some victims need a bottle of plasma every four hours for a

YOUNG VISITORS: Mayor Jean Drapeau entertained two young visitors yesterday in connection with the Red Cross drive for more blood donors to combat the seasonal shortage of blood for hospitals. Michel Gervais, 7, centre, a "blue baby," who has required many pints of donors'

year-old David Page, another youthful suffere from a disease requiring large amounts of bloo are seen looking at Mayor Drapeau's visitor book. A blood donor clinic will be held in th south pavilion of Lafontaine Park Restaura on Tuesday, Aug. 1.

Montreal Canadiens' Hall-of-Famer, Maurice Richard, with Marc Dagenais, a 6-year-old boy with hemophilia from Ottawa.

Maurice Richard, joueur étoile des Canadiens de Montréal, en compagnie de Marc Dagenais, un garçon hémophile de 6 ans d'Ottawa.

An Ontario Chapter picnic attended by founding members Alex Paul, Joyce Rosenthal, Earl Lock, Mary Smith and lois Bedard (seated). Circa 1959.

Un pique-nique de la Section Ontario (vers 1959) auquel participaient les membres fondateurs Alex Paul, Joyce Rosenthal, Earl Lock, Mary Smith et Lois Bedard (assise).

The CHS Officers, Trustees and members of the Medical and Scientific Advisory Board in 1958

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SCHQ

Le Conseil d'administration de la **Section Québec** tient à souligner le 50^{e} anniversaire de la Société canadienne de l'hémophilie avec enthousiasme !

Voilà un demi-siècle de valeureux services offerts aux personnes atteintes de troubles de la coagulation, grâce à l'ardeur de ses bénévoles et à la compétence de son personnel.

Bravo… et encore longue vie !

The Board of Directors of the **Quebec Chapter** wishes to congratulate the Canadian Hemophilia Society on the occasion of its 50th Anniversary!

A half-century of valiant service to people living with bleeding disorders, thanks to the dedication of its volunteers and the professionalism of its staff.

Bravo… and keep up the good work!

Best wishes to the entire bleeding disorders community from the 2002/2003

EXECUTIVE COMMITTEE

of the

Canadian Hemophilia Society.

We are proud to serve our members and look to the future with great optimism.

Meilleurs vœux à toute la communauté des personnes atteintes d'un trouble de saignement, de la part du

COMITÉ EXÉCUTIF

2002-2003 de la

Société canadienne de l'hémophilie.

Nous sommes fiers de nos réalisations et entrevoyons l'avenir avec optimisme.

Charles C. J. Kubin (left) and Ray Daniel (bottom), founders of the Manitoba Chapter in 1962.

Charles C. J. Kubin (ci-contre) et Ray Daniel (en bas), fondateurs de la Section Manitoba en 1962.

Captain Dick Rudd, here with his wife Janet, was the driving force behind the creation of the British Columbia Chapter in 1959 and 1960.

Le capitaine Dick Rudd, photographié ici avec son épouse Janet, a joué un rôle déterminant dans la fondation de la Section Colombie-Britannique en 1959 et 1960.

CONGRATULATIONS

CANADIAN HEMOPHILIA SOCIETY

Your Manitoba Chapter salutes you
For tireless advocacy
representing our interests
For seeking to meet our needs
through persistent hard work and for
improving the lives of those
affected by bleeding disorders
for 50 years
Thank you

The British Columbia Chapter has over four decades of history to be remembered.

The driving force in the creation of a provincial chapter in British Columbia was **Captain Dick Rudd**. In 1959, along with his wife Janet, daughter Teresa and son Bill he moved back to BC from Ontario. Other individuals that played a vital role in the establishment of the chapter include **Martin Dayton**, **John Harkness** and **Margaret Thompson**. Although their work began in 1959, the BC Chapter wasn't officially registered until 1960.

Margaret Thompson, who had already been a member of the National Society was always on the lookout for more people with Hemophilia in the Vancouver area. She soon found other families to join the organization: the Douglases, the Martellis, the Koops, the Tylers, the Prantes, the Irelands, the MacKenzies, the Fultons and the Pearkes. They were soon joined by the Mumfords, the Moss', the Waines, the Mitchells and many others.

At first, meetings were held in the homes of the members. By 1970 the location was at the Kinsman office and eventually the meetings moved to the Mary Pack Arthritis Centre.

Right from the beginning stages of the chapter, the production of a newsletter *"The BC Chapter News"* later renamed the *"Transfusion"* commenced with the intent to form a vital link throughout the community. Though it went into hiatus for a period of time, it was reintroduced again seven years ago under the same name. Our quarterly newsletter continues to play an important role in providing our community with pertinent, up to date information.

One of the early fundraising activities includes the famous and well remembered "Mothers March of Dimes". Volunteers were able to blitz the West End of Vancouver from Burrard Bridge to Stanley Park in one single night. With the great help of **Jake Koop** and his fellow church members going door-to-door they collected $10,000. Jake Koop was also instrumental in helping the community by organizing blood drives and together with **Dr. Wally Thomas** (hematologist who aided parents in starting the chapter) they worked diligently to educate the public about Hemophilia.

In an effort to bring people together and to strengthen the community bond, an annual social night was held where as many as 60-70 people would gather.

Dr. Gerry Growe, who worked with Dr. Thomas, had his initial contact with the Society in 1971 at a meeting held in Vancouver. The Hemophilia Assessment Clinic started in 1972, the first in Canada. The first nurse was **Connie Prokop IV,** a therapy nurse, who worked part time for Vancouver General Hospital and part time for the Clinic. **Lois Lindner,** our current Hemophilia Nurse Coordinator, joined the Clinic staff in 1978.

Interesting adage to the history and diagnostic of hemophilia: In 1952, **Stephen Christmas** from Vancouver was the first person to be diagnosed with Factor IX (currently known as Christmas disease).

On behalf of the BC Chapter, we would like to take a moment to express our gratitude to National for their support, advocacy and their tremendous hard work. The Canadian Hemophilia Society always stood up for its members, and was our protector that provided a loud voice when crisis arose. We are proud to be part of this National organization and we need to thank all its dedicated staff members for their leadership, their guidance, their understanding and their compassion towards persons with Hemophilia and other victims of the tainted blood scandal. Without a strong National office we couldn't have achieved our goals.

MAJOR MILESTONES: 1953-62

1953	CHS founded
1954	First concentrated FVIII from pig's blood
1955	First adult HTC in Canada – St. Mary's Hospital, Montreal
1955	First attempts in U.S. at making antihemophilic globulin (AHG), now called factor VIII concentrate, from human blood
1956	First-ever successful appendectomy in a hemophiliac, Montreal
1957	Ontario Chapter founded
1958	First experiments in prophylaxis in hemophilia A in Sweden
1959	Quebec Chapter founded
1960	BC Chapter founded
1960	First AHG, manufactured by Connaught from Red Cross blood, infused into a Canadian hemophiliac — Bill Rudd
1960	First dogs ever diagnosed with hemophilia B, at Ontario Veterinary College, Guelph
1961	Hyland Laboratories begin work on commercial factor VIII concentrate
1962	Manitoba Chapter founded

ÉTAPES DÉTERMINANTES : 1953-1962

1953	Fondation de la SCH
1954	Premier concentré de facteur VIII tiré du sang de porc
1955	Premier centre de traitement de l'hémophilie pour adultes au Canada – Hôpital St. Mary's, Montréal
1955	Aux États-Unis, premières tentatives de fabrication de globuline antihémophilique (AHG), maintenant appelée concentré de facteur VIII, à partir de sang humain
1956	Appendicectomie d'un hémophile réussie pour la première fois à Montréal
1957	Fondation de la Section Ontario
1958	Premières expériences de prophylaxie pour l'hémophilie A en Suède
1959	Fondation de la Section Québec
1960	Fondation de la Section Colombie-Britannique
1960	Première perfusion de globuline antihémophilique, fabriquée par Connaught à partir de sang de la Croix-Rouge, chez un hémophile canadien — Bill Rudd
1960	Premier diagnostic d'hémophilie B chez un groupe de chiens, au collège vétérinaire de l'Ontario à Guelph
1961	Hyland Laboratories commence ses travaux pour fabriquer commercialement du concentré de facteur VIII
1962	Fondation de la Section Manitoba

Fev. 1960

Peanut Called a Hemophilia Aid

An Afflicted Scientist Finds Diet of Nuts Curbs Bleeding

By JOHN A. OSMUNDSEN

The lowly peanut may become the conqueror of the disease of kings.

Something in the meat of that seed, an American scientist has found, appears to be capable of stemming the flow of blood in hemophilia. This is the so-called "bleeders' disease," notably associated with royal families.

The discovery was one of those curious accidents that sometimes happen when the time and all the circumstances are ripe.

In this case, the time was a morning in May, 1957. Dr. H. Bruce Boudreaux awoke at his home in Baton Rouge, La., and

Wirephoto / The New York Times

Dr. H. Bruce Boudreaux in laboratory at Ba n Rouge, La.