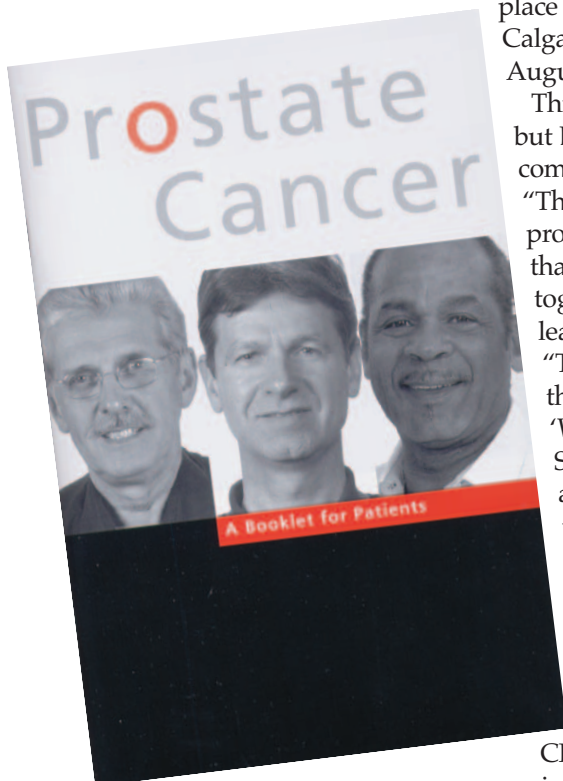


## New booklet catching on

Prostate cancer survivors all know how badly men need information and support during that critical period in between diagnosis and treatment. That's the time when a number of very important decisions must be made. CPCN's new booklet Prostate Cancer. A Booklet for Patients was designed with precisely those needs in mind.

Concise and written in layman's language, the 50-page booklet begins with an overview of cancer and then moves into the specifics of prostate cancer diagnosis and treatment. It also covers various treatment options and contains a good section on support services and resources. As a bonus, the booklet comes with a copy of Prostate Passport, a handy notebook, designed to help patients record and keep track of important information about medical history, appointments, treatments, test results, medications and questions to ask your doctor at the next visit.

Copies of Prostate Cancer. A Booklet for Patients have been



distributed in limited quantities to all Canadian prostate cancer support groups and orders are starting to roll in from practitioners and clinics.

Early response to the booklet has been very enthusiastic. Accolades have come from as far away as Europe. Dr. Louis Denis, a world-wide authority on prostate cancer from Antwerp, Belgium was particularly impressed with the Prostate Passport, so much so that he wrote to CPCN asking for permission to copy parts of it in a similar that he and his associates are developing for use in Europe. "We consider (the diary) a wonderful initiative," he wrote. "As a matter

*continued on p. 4*

# Canadian Prostate Cancer NETWORK

March 2004

NEWS

## Come on out to Calgary!

Did you ever wonder how much you could learn by mingling with prostate cancer survivors, activists and experts from across the country? Have you ever had a hankering to have a drink with some of the movers and shakers you read about in this newsletter? This summer you'll get your chance.

CPCN is sponsoring Canada's first ever national conference for prostate cancer support and awareness groups this coming August in Calgary. The conference, a vision of CPCN president, Bob Shiell, will take place at the Fairmont Palliser, Calgary's grand old hotel, on August 8, 9 and 10.

This event will be multi-faceted but Bob sees it primarily as a coming together of support groups. "The reason I undertook this project is that I feel very strongly that support groups should come together, to meet and greet and learn from one another," he says. "That's why we decided that the theme for the conference will be 'Working Together Works.' Stronger support groups mean a stronger CPCN and that puts us all in a much better position to advocate for improved treatment and research for prostate cancer."

Therefore, in addition to updates on the latest medical advances and research, the CPCN conference will feature seminars on topics of direct interest to support groups. There will be break-out sessions on media relations, how to advocate in your community, team-building, fundraising and leadership development. "We want this to be the beginning of an ongoing exchange of ideas and training," says Bob.

Keynote speaker will be world-renowned oncologist, Dr. Stephen Strum, who has specialized in prostate cancer for the past 20 years. Dr. Strum is co-founder and medical director of the Prostate Cancer Research Institute in Los Angeles, California, and also co-author of A Primer on Prostate Cancer. The Empowered Patient's Guide. He is just the first of many eminent professionals who have indicated

interest in being part of this conference.

Final program details are still to be worked out, but the conference will begin with registration on Sunday afternoon and run until about midday on Tuesday. Expect to receive more details about the conference program, along with information about how to register, in the mail.

The cost for the conference package, which includes all information sessions, seminars, social events and meals, will be <<TBA>>. Attendees should make their own arrangements for accommodation. Those wishing to book a room at the Fairmont Palliser can do so by calling 1(800) 257-7544 or by visiting the hotel's website: [www.fairmont.com/palliser/](http://www.fairmont.com/palliser/).

Conference information will be posted on the CPCN website as it becomes available.



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# Otto Tucker – A Pioneer from “The Rock”

Otto Tucker has never been one to shy away from pithy statements about the realities of life after prostate cancer treatment. Diagnosed with prostate cancer at age 70, the St. John's, Newfoundland resident underwent a radical prostatectomy and has lived with a external catheter ever since. And he doesn't mind talking about it.

One quote attributed to him has become somewhat legendary. Otto says it seems to have made it's way right across Canada, but most versions are inaccurate, he says and he welcomes this opportunity to set the record straight. “What I really said was, “I'm the one of the few people who can preach and pee at the same,” he chuckles. We'll leave it to the reader to imagine the various ways that statement, made to a large gathering in St. John's, might have gotten twisted and fractured over the years.

When Dr. Tucker is not tossing off witticism's about life after prostate cancer surgery, he does a lot of work for the St. John's Prostate Cancer Support group he helped to found shortly after his illness, about ten years ago.

Otto was born and raised in Winterton, a small fishing village on Newfoundland's Trinity Bay. He started out as a school teacher and principal, went back to school to get his doctorate and then went on to become a professor of education at three different universities, Toronto, Acadia and Memorial before retiring to St. John's.

“We have a very dynamic group here,” he enthuses. “We get 70 or 80



people out each meeting and we go out and make presentations to church groups and other community groups.”

One unique service of the St. John's group is the one-to-one support offered to men from isolated areas who come into St. John's for their prostate cancer treatment. Otto takes great pride in this service. “We have a number of men coming in from the outlying areas where there are no support groups and we provide them with one-on-one support,” he explains. “The local doctors know that they can call the Cancer Society who will contact us and we will arrange for one of our members to go and visit the fellow

and offer him support.”

Only recently, Dr. Tucker had the opportunity to do some counselling with a “young chap” (This man was 65. Otto is 80 years young.) who was apprehensive prior to his diagnostic procedure. After a session with Otto, the man felt greatly comforted and much more certain about how best to face his future. Otto says that providing this kind of one on one support is very rewarding and satisfying. “People might think that being involved with cancer is a downer, but it's not a downer at all,” he says. “In fact, it's very optimistic. It can be a very uplifting experience.”

## Orillia – small but mighty

The Orillia Prostate Cancer Awareness Group celebrates it's third anniversary next month. Orillia is a town of 30,000 located in a picturesque setting where Lakes Simcoe and Couchiching come together about 70 miles north of Toronto.

Orillia's prostate cancer group, formed in April 2001, meets 8 times a year at the local Royal Canadian Legion. Like others, the Orillia group tries to build each meeting around a speaker, presentation or roundtable discussion on a certain topic. “We've had some of our local professionals in and several speakers have come up from Toronto including Dr. Ross Gray, a psychologist at Sunnybrook Health Centre and Dr. Charles

Catton a radiation oncologist from Princess Margaret Hospital,” says executive committee member, Ray Powis.

Ray estimates that 25 to 40 men (sometimes with spouses) attend each meeting and that the groups membership has surpassed the 100 mark. Not bad for a small town.

“We don't use the word members, though,” says Ray. “At the beginning, we found that people thought being a member might mean that they'd have to pay dues and that we'd expect them to show up at every meeting. So we just call them attendees and that seems to keep everybody happy.”

One challenge faced by new groups is succession. Often a group's early success depends on a small cadre of go-getters willing to roll up their sleeves and do the organizational work necessary to get things going and see the group through it's formative years. What happens when they are ready to move on?

Ray says the Orillia group hasn't really faced that yet since the original executive is still intact. But they have found a way to ease new people into greater hands-on involvement. He explains. “We have a form for new attendees to fill out with their contact information so we can phone, e-mail or fax them about upcoming meetings. One thing we ask on that form is if people want to

be part of the executive. Some attendees do indicate interest, but Ray says they are often a little reticent when contacted directly about coming on the executive “So what we do is try to find a specific task that they are comfortable doing and get them involved that way,” he says.

“Someone might not like the idea of being on the ‘executive’ but they be happy to help with their ideas, put

up posters or join the telephone committee.”

The group is hoping that one or two members of the phone committee will eventually join the executive.

On another note, Mr. Powis' own involvement with the group came about via an unconventional route. He actually joined and even served on the executive before he had prostate cancer.

“I knew I was getting to the age when many men develop prostate cancer

so I wanted to find out more so I'd be prepared if I ever had to go down that road,” he says. As it turned out, Ray was diagnosed with prostate cancer last year and underwent surgery. He feels that his involvement with the support group made a big difference. “When the doctor told me I had prostate cancer, it didn't seem like nearly as big a deal as I might have thought,” he recalls.

“Throughout the entire process my experience with the support group really worked in my favour.”



Dave Anderson takes the message to the street.

## Combined Androgen Blockage – Yes or No?

The current of standard treatment for advanced prostate cancer is androgen deprivation with a single drug. Combined androgen blockade (CAB) is a form of androgen deprivation that uses a combination of drugs to provide more thorough androgen deprivation by blocking most of the body's production of testosterone and minimizing the impact of the remaining testosterone, thereby slowing the tumour's growth.

Recently there has been some controversy as to whether or not the benefits of CAB outweigh the negatives. Some experts have suggested that the benefits are too small to be considered clinically significant. Others disagree. What is interesting is that while CAB for advanced prostate cancer has been called into question, the corresponding treatments for advanced breast, colorectal and lung cancer have not been challenged.

A team led by Canadian urologists (and medical advisors to CPCN) Dr. Armen Aprikian and Dr. Neil Fleshner compared the benefits and costs of CAB in advanced prostate cancer with the benefits and costs of similar treatments used in advanced

breast, colorectal and lung cancers. They found that, on a statistical basis, the benefit of CAB, that is, the amount by which it extended survival was modest: three months on average. However, that benefit was similar to that derived from standard later-stage treatments for the other cancers. Moreover, CAB was shown to have the same or lower cost and to have fewer side effects.

In an editorial in the October 2003 issue of The Canadian Journal of Urology, where these results were published, Dr. Laurence Klotz, urologist and editor-in-chief of the journal challenged the nay-sayers noting: “This [research] is an important contribution to the literature. We should embrace the modest survival benefit of MAB\* and offer it to appropriate patients.” \*MAB stands for maximum androgen blockage, another term for CAB.

Whether or not individual prostate cancer patients can benefit from CAB will depend on a number of factors which will vary from case to case and which are best discussed between doctor and patient.



OPCAG members at Garfield Dunlop's M.P.P. Senior Day. From left to right: Gordon Langman, Garfield Dunlop, Jack Shenton, Colin Wackett, Fritz Sawade.

# On a roll with Red

The Red Green campaign is gathering steam. Last issue, we reported that Steve Smith, known to his fans as Red Green, had generously donated his time and his character to aid the cause of prostate cancer awareness. In October 2003, St. Joseph's Healthcare Hamilton partnered with the Canadian Prostate Cancer Network to produce two 30-second public service announcements featuring Red which highlight the importance of regular prostate exams for men over age 50.

Those PSAs have begun to hit the airwaves, and depending on where you live you may have already seen or heard one. The FAN 590, an all-sports radio station in Toronto, began airing one of the announcements in January and other television and radio stations across Canada will follow suit as PSA spots become available. All of the major Canadian television networks CBC, CTV, CanWest Global and CHUM Television (CITY TV in Toronto, Bravo, Much Music) have signed on. The Red Green spots will also play on the Weather Network and the Patient Network, an in-hospital educational television channel. At press time, radio exposure had been secured on a number of radio stations,

mainly in southern Ontario. Radio coverage is expected to grow quickly.

This impressive campaign, which would have cost thousands if it had been provided by a public relations firm, was put together for CPCN at no charge by the kind people in the Marketing & Community Relations Department of St. Joseph's Healthcare Hamilton.

Not only did they secure mass media coverage, St. Joseph's also pursued some very interesting alternative venues to reach the PSAs target audience.

St. Joseph's approached several National Hockey League franchises and arranged for the public service announcements to air in the hockey arenas during game nights. In a few weeks, the Red Green spots will be

shown on the Jumbotron during Toronto Maple Leaf playoff games. Similar spots are confirmed at the Corel Centre in Ottawa and HSBC Arena in Buffalo. Approval for the Saddledome (Calgary Flames) and General Motors Place (Vancouver Canucks) is pending.

St. Joseph's also contacted Hi-Rise Communications, a company that organizes elevator advertising in Canadian cities. Through this partnership, St. Joseph's secured approximately 300 no-cost print advertising opportunities for the Canadian Prostate Cancer Network. Posters, carrying the same message as the PSAs will soon appear in 300 elevator advertising locations in major Canadian cities.

In case you haven't seen or heard one of the spots yet, the approach is very much what you'd expect from Canada's king of duct tape. He resists the urge to become overly earnest and serious. Instead, Red employs his characteristic homespun, male-oriented humour to drive home the message that men over 50 should see their doctor and get themselves checked for prostate cancer. As Red says, "You're never too old to do something smart."



Shooting the television spot in CBC's studios in Toronto.

## CPCRI funding not renewed

The Canadian prostate cancer community was disheartened to learn recently that Health Canada decided not to renew funding for the Canadian Prostate Cancer Research Initiative (CPCRI).

For the past five years, the CPCRI has provided a focal point for prostate cancer research in Canada. The CPCRI has worked to build networks, foster cooperation among researcher and encourage innovative projects.

Funding for the CPCRI came about as a result of the national prostate cancer forum which took place in 1997. Although there was never any guarantee that the funding would be renewed after five years, Dr. Stuart Edmonds, CPCRI's director, says there were strong hopes that Health Canada would find a way to keep the dollars flowing. He explains, "We had assumed that since Health Canada was providing ongoing funding for breast cancer research, they would make a similar commitment to prostate cancer, another gender specific cancer." A select committee of the CPCRI had asked Health Canada to commit 10 million dollars over the next 5 years.

However, those hopes were dashed last January when members of that committee, were told at a meeting in Ottawa, that Health Canada would not be renewing its financial support for the CPCRI. The official explanation, provided by Associate Deputy Minister, Janice Charette, was that the dollars provided for the CPCRI five years ago were always intended to be one-time funding which was coming to an end. She also noted that Health Canada was moving away from away from funding initiatives specific to one kind of cancer.

Neil Berman, Executive Director, at Health Canada, of Canadian

Strategy for Cancer Control says the current strategy is to fund broad projects or initiatives relevant to cancer in general as opposed to specific types of cancer. "We're trying to do something across the board, rather than fund initiatives that is specific to tumor sites," he says.

This change in strategy came about as the result of consultations with various stakeholders over the past few years. An alliance of Canadian research funders, including Health Canada and the Canadian Institutes for Health Research (CHIR) consulted with various professional and consumer groups to determine new directions for cancer research. Berman says the alliance was somewhat surprised at what stakeholders said. "In fact, we had expected that people would ask for more funding related to specific tumour sites," he explains. "But instead they wanted to identify fields of research which would benefit lots of cancer." This doesn't mean there can be no research at all that is specific to any given type of cancer, nor that there will be no research in the prostate cancer field. "Prostate cancer researchers can apply for funding just like researchers in other cancers," Berman notes adding that he knows of 34 CHIR-funded, prostate cancer research projects currently underway in addition to those funded by the CPCRI.

Edmonds counters that in many of those projects, prostate cancer is only part of the focus of research, not the prime focus as was the case with research funded through CPCRI. "Some issues are specific to prostate cancer," he says. "That's why we need to sustain the focus that the CPCRI can provide."

The loss of Health Canada funding, which accounted for about two-thirds of CPCRI's funding, does not spell the immediate demise of the CPCRI, however, Edmonds says it will be a big blow. "We have enough money to fulfil our current commitments, but we won't be able to take on new projects. Losing two-thirds of our funding is a big blow, obviously." The CPCRI is looking for new partners, but Edmonds says that the loss of Health Canada's support will almost certainly have a chilling affect on other potential partners. "Health Canada pulling out sends a signal to other possible funders that your project is not a priority. That doesn't help."

The unanswered question here is, why does the Canadian Breast Cancer Initiative get ongoing funding, while the CPCRI does not. There are two answers to that question. One is that Breast Cancer was, in a sense, in the right place at the right time. The call for Breast Cancer Research came along at a time when the government was responding to calls for funding for women's health issues and when Health Canada was funding medical initiatives related to specific types of cancer.

Moreover, funding for the Breast Cancer Initiative came about largely a very strong lobby. If it were taken away now, there would most likely be a strong wave of political protest. In contrast, the CPCRI funding came about because of consultation. The federal government has never experienced the same level of political pressure around prostate cancer as it has felt around breast cancer.

Jack Brill might have something to say about that. Jack, a CPCN Director and Maritime Coordinator,

has found a valuable ally in the Honorable Geoff Regan, Member of Parliament for Halifax West, Minister of Fisheries, and Minister for Health Policy. Mr. Regan agrees that Health Canada's funding for the Canadian prostate Cancer initiative should be renewed.

In a letter to Jack dated January 30th, Minister Regan stated: "In response to your letter of January 16th 2004, I wanted to let you know that I have written to the Honorable Pierre Pettigrew, Minister of Health asking his Department to provide continued funding for the Canadian Prostate Research Initiative and expressing my strong support of programs such as this that promote prevention."

Neil Berman said he couldn't comment on what impact Minister Regan's letter might have. What he did say was that "In general, decisions that involve significant allocations of federal funding are made by Cabinet of the government in office. If a federal minister wishes to establish or renew a program that requires additional funds over and above their department's main estimates that are approved by parliament, they present a proposal to Cabinet for decision."

In other words, the government might respond to lobbying, and our government has clearly experienced enough lobbying on behalf of prostate cancer.

What can you do? Talk to your MP. There's an election coming. What better time to talk to politicians who want your vote. If you are a survivor, or just an interested party, please continue to write, email or visit your MP and tell him or her that this Initiative is important and must be continued. Direct links to all federal MPs can be found on the CPCN website.

# President's Message



Please consider this your personal invitation to "Come Together in Calgary" for the First Canadian Prostate Cancer Network National Conference. The conference will take place in

Calgary at the beautiful Fairmont Palliser Hotel ([www.fairmont.com/palliser](http://www.fairmont.com/palliser)) from Sunday afternoon August 8 to Tuesday afternoon August 10th. Since Calgary offers many attractions and is only a little over an hour from the beauty of Banff, Lake Louise and the Canadian

Rockies you might want to consider staying longer either before or after the conference. We have negotiated an excellent rate of \$129 per night, single or double, and children stay free.

As I write we are confirming both the scientific and social programs and speakers. We are thrilled the Dr. Stephen Strum has agreed to be a key note speaker. You can be assured that both the scientific and social programs will make your attendance worthwhile! More details will soon be posted on the CPCN web site. If you have any questions just drop me a email at [bobshiell@shaw.ca](mailto:bobshiell@shaw.ca)

The theme of the conference, "Working Together Works" is particularly meaningful as we struggle

with the federal government to secure research funding for the Canadian Prostate Cancer Research Initiative. As you may remember, Health Canada initially funded a 5 year program with a 5 million dollar grant. This initial 5 year program is now over and meetings with Health Canada officials indicate that additional funding to allow the program to continue will not be forthcoming. It is interesting to note that research funding for breast cancer is continuing. Perhaps a letter or phone call to your MP would be appropriate.

I'm looking forward to meeting you personally in Calgary in August.

## Anemia: something to think about

When you have cancer, the word anemia probably doesn't even appear on your radar screen. But it should. Many cancer patients, including those with prostate cancer, develop anemia. Untreated, anemia can affect the effectiveness of your treatment and how you feel as you recover.

There are several different kinds of anemia, but essentially, it means that your body is not making enough red blood cells. Red blood cells contain hemoglobin, an iron-rich protein that carries oxygen to organs and tissues.

Therefore the core issue with anemia is that your body's cells don't get the oxygen they need. That has two main results. One is that it can make you feel tired, weak, short of breath or dizzy. The other is that your body detects the lack of oxygen and tries to compensate by making the heart work harder. The heart pumps harder and your blood vessels try to open up a little wider to allow more blood to go through. This can increase the risk of heart attack if you have underlying heart disease.

Cancer patients can develop anemia for several reasons. First, cancer disrupts various bodily mechanisms including the bone marrow's ability to make red blood cells. Anemia can also be a side effect of treatment. Bleeding due to surgery can cause temporary anemia. However, improved surgical techniques have made this less common in prostate cancer.

Prostate cancer patients undergoing hormone and radiation therapy are also at increased risk for anemia. Anti-androgen therapy suppresses the body's response to erythropoietin, the hormone that triggers the bone marrow's production of red blood cells. Radiation treatment can reduce the function of the bone marrow.

On the flip side, having anemia can affect both the effectiveness of cancer treatment and the quality of your recovery. Radiation treatment, for example, works best when the body's cells are "lively" that is well oxygenated, which is not the case in anemic patients. Anemia also makes it more difficult for your body to recover from surgery.

Bottom line: all prostate cancer patients should be thoroughly assessed and treated for anemia prior to undergoing cancer therapy and then monitored during the recovery period.

The standard first-line treatment for anemia is to increase the patient's intake of iron through diet or iron supplements. The hemoglobin in the red blood cells require oxygen in order to work properly. However, if the real problem is that you don't have enough red blood cells in the first place, more iron won't solve the problem, says Durhane Wong-Rieger Phd, President of the Toronto-based Anemia Institute. "It's important to ask your doctor to determine the

underlying cause of your anemia," she says. "There can be a number of different causes which require differing treatments."

When anemia cannot be treated with diet or iron supplements, patients maybe treated with doses of erythropoietin and in more drastic cases, blood transfusions. "We advise all patients with prostate (or any other) cancer to talk to their doctor about anemia, both before treatment and afterwards," says Wong-Rieger.

## CPCN website news...

If you've visited the CPCN website you'll know that it contains a wealth of information. Next time you're on the site ([www.cpcn.org](http://www.cpcn.org)) don't forget to take a look at the newsletters which are available to all visitors. The right hand side of the CPCN homepage has links to thirteen different publications including support group newsletters from several different Canadian provinces including Newfoundland Quebec, Ontario, Manitoba, Alberta and British Columbia.

Not only do these newsletters offer a window on the activities of other support groups, they are also a surprising source of valuable information. That's because, along with local news and announcements, some newsletters have very good general interest articles on various prostate cancer related topics.

For example, the January 2004 edition of Pathfinder, from Prostaaid, in Calgary, has an interesting piece on a cryotherapy, a new less-invasive

surgical method which uses new and advanced targetting and freezing technologies to destroy only the portion of the prostate affected by cancer. The Aug. 2003 newsletter of Montreal West Island Prostate Cancer Support Group contains notes from address made to that group by Dr Luis Souhami, a radiology oncologist from McGill University. The Kelowna Newsletter has articles about three different studies, one on the long-term effectiveness of Viagra, another which looks at how satisfied men are with their prostate cancer treatment, and one which shows that the effectiveness of radiation therapy can be predicted as early as three months post-treatment.

The CPCN website also has links to online versions of Our Voice Magazine and the newsletter of the Cancer Research Institute of Ontario. All newsletters are available for download and can be copied to provide information to those support

## New booklet catching on...

*continued from p. 1*

of fact we would like to use some parts of it."

Individuals, Support Groups and other interested organizations may order the booklet via the email address on the CPCN web site. Individuals may also pick up a copy at their local support group meeting. We are also hoping that support group members will let medical professionals in their area know that the booklet is available. Take a copy to your local urologist or office of the Canadian Cancer

Society and let them know how they can order copies.

One thing that Tom Gentles, of the Regina PC Support Group, likes about Prostate Cancer. A Booklet for Patient is that it can be used to get information to men at a critical time. "Support groups can play an important role in finding ways to get information to men in the critical period in between diagnosis and treatment. This booklet can help us to do that."

## SUBSCRIPTIONS

There is no charge to receive the Canadian Prostate Cancer Network news. However, to help us keep our records up to date and to ensure that you continue to receive future copies, please fill out this form and return as soon as possible to: CPCN, Box 1253, Lakefield, Ont. K0L 2H0)

**(Please note that this is for individual copies only.)**

Name: \_\_\_\_\_

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