

**La Corporation Félix Hubert d'Hérelle**

**Annual Activity Report  
2000-2001**

# Table of contents

|  |           |
|--|-----------|
| WORD FROM THE EXECUTIVE DIRECTOR .....                             | 3         |
| <b>1. OUR MISSION.....</b>   | <b>6</b>  |
| <b>2. PORTRAIT OF THE CLIENTELE .....</b>                          | <b>8</b>  |
| EVOLUTION .....  | 8         |
| PROFILE OF THE RESIDENTS .....                                     | 11        |
| <b>3. A FEW FACTS ON HOUSING.....</b>                              | <b>20</b> |
| ADMISSION REQUESTS .....   | 20        |
| RETURNING TO THE COMMUNITY .....                                   | 22        |
| <b>4. ACTIVITIES .....</b>   | <b>24</b> |
| SUPPORT FOR LOVED ONES .....                                       | 24        |
| VOLUNTEERING.....  | 25        |
| COMPLEMENTARY OR ALTERNATIVE APPROACHES TO HEALTH MANAGEMENT ..... | 32        |
| TRAINING .....   | 34        |
| PROMOTIONAL ACTIVITIES AND OUTSIDE COLLABORATIONS.....             | 35        |
| <b>5. FINANCIAL RESOURCES.....</b>                                 | <b>38</b> |
| <b>6. PERSPECTIVES FOR THE FUTURE .....</b>                        | <b>40</b> |
| <b>ANNEX.....</b>  | <b>42</b> |

## Word from the Executive Director

It is with great pleasure that I present to you the annual report of la Maison d'Hérelle for the fiscal year ending March 31<sup>st</sup> 2001.

The year 2000-2001 was marked, on the one hand, by our evaluation of the SAGs (Shared Appreciation Groups) and, in December, by the fundraiser organized to celebrate the 10th anniversary of la Maison. The SAGs, chaired by the members of *la COQ-sida* (the *Coalition des organismes québécois de lutte contre le sida*), were created to ensure that la Maison's admission criteria reflected adequately the organization's mission. The activities surrounding the 10<sup>th</sup> anniversary contributed to highlight la Maison's existence in areas we had not been able to sensitize in the past.

The descriptive and statistical presentation that follows will reflect, I hope, as faithfully as possible, the day to day life of la Maison and the values that are circulated there, through our daily gestures.

In this context, where persons living with HIV-aids are seeking support for their « return to life », new therapies, community living and support amongst peers, it is the tenacity of these persons which encourages us to take up the challenges as an organization but also, as a collective. While some still die, too young and too tired of the fight, we are still inspired to give the best of ourselves between moments of mourning and moments of hope.

From one year to another, la Maison d'Hérelle adjusts itself and seeks to answer the needs of a clientele that is more and more diverse and in despair. All that follows in this report is witness to these facts.

I wish to thank the team of workers and the volunteers for their professionalism, their commitment and especially, their sense of humour...

Thank you also to the members of the Board of Directors for their devotion and in particular, to Dr. Richard Morisset for the years he presides the Board of la Maison from its founding to December 2000.

And finally, thank you to the residents, who continue to teach us about life.

Pleasant reading.

***Michèle Blanchard***



# 1. Our mission

La Corporation Félix-Hubert d'Hérelle<sup>1</sup> is a non-profit organization which has been pursuing its mission since its creation in 1989.

Created through an initiative of the Quebec Ministry of Health and Social Services, the City of Montreal and Centraide, la Maison d'Hérelle is a community residence for persons living with HIV-aids, experiencing loss of autonomy. It is able to welcome 17 residents.

May be admitted at la Maison d'Hérelle any person living with HIV/aids, who is experiencing loss of physical or psychological autonomy, requires housing (palliative care, transition, convalescence or rest) or support, and this, without any form of discrimination. The principal ailment must, however, be directly related to HIV-aids.

## Objectives :

- To offer adapted community housing to persons living with HIV-aids;
- Provide care while stimulating autonomy in our residents and encourage them to take an active part in their quality of life;
- Provide support for loved ones;
- Ensure post-departure assistance.

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<sup>1</sup> Félix-Hubert d'Hérelle was a microbiologist born in Montreal April 25th 1873. After completing his studies in medicine in France, he held research positions in a dozen countries. It was during the course of his tenure at the *Institut Pasteur* in Paris that he will discover, in 1918, the phenomenon of bacterialphagia. A bacterialphage is a virus which acts as a parasite to other viruses and destroys them. His discovery influenced the work of a great number of researchers in the field of infectious diseases.

**Philosophy :**

Our work is based on the pursuit of quality of life and the reduction of the stress associated with the difficult living conditions of persons living with HIV-aids.

In the spirit of multiple expertise, a team develops, with each resident, an integrated approach which takes into account the dimensions of the individual.

We seek to provide a warm and humane environment, respectful of individual aspirations, choices and differences.

## 2. Portrait of the clientele

### Evolution

Data collected this year and over the past 11 years has allowed us to draw the following portrait of our clientele:

#### *Number of resident sand type of care*

Since the opening of la Maison d'Hérelle in May 1990, we have welcomed **302** residents. This year, 56 persons were cared for, 8 more than last year. Among those, 30 were in transition, some 16 more than last year. This clearly indicates to us that this type of care is on the increase.

**0** between 1992 and 1997;

**5** in 1997-1998;

**11** in 1998-1999;

**14** in 1999-2000; and

**30** this year.

The tendencies we observed reflect the significant importance of requests for convalescence care, temporary rest or short term care.

The majority of requests for this type of assistance comes from persons currently under hospital care and the main objective of their stay at la Maison d'Hérelle is to get assistance in receiving the benefits of the antiretroviral therapies.

## *Age at admission*

Since it opened, the average age of residents at la Maison d'Hérelle is approximately 40 years old.

## *Gender*

Our data reflects those of the health authorities (*Régie Régionale*, figures at December 31st 2000) : « *Men still represent more than 88% of all cases...* ».

La Maison d'Hérelle has welcomed a majority of men, 87%, in the past 11 years. This year, 18% of our clientele were women. In the last three years, we have observed an increase in requests from women:

6 in 1998-1999;  
7 in 1999-2000; and  
10 in 2000-2001.

## *Sexual orientation*

This year, we welcomed an equal number of heterosexual and homosexual persons::

42,9 % homosexuals  
42,9 % heterosexuals

## *Reasons for departure*

In general, the most remarkable and encouraging fact is the increasing number of persons returning to live at home. In fact, last year, 44% returned home but this year, the proportion rose to 63,5%.

## *Number of deaths*

13 persons died this year, during the course of their stay. Among those, 8 occurred at la Maison d'Hérelle while 5 occurred shortly after admission at hospital.

## *Occupancy rate*

### **Palliative care and transition :**

|                                     |              |
|-------------------------------------|--------------|
| Number of days of occupation        | 4 671        |
| Total capacity (16 beds X 365 days) | 5 840        |
| <b>Percentage of occupation</b>     | <b>80,0%</b> |

### **Short term care :**

|                                     |              |
|-------------------------------------|--------------|
| Number of days of occupation        | 139          |
| Total capacity (16 beds X 365 days) | 365          |
| <b>Percentage of occupation</b>     | <b>38,1%</b> |

## *Associated disorders*

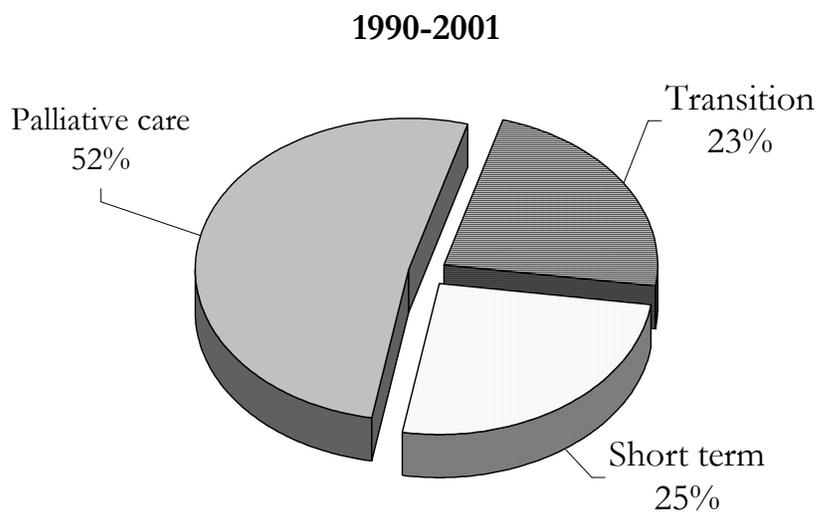
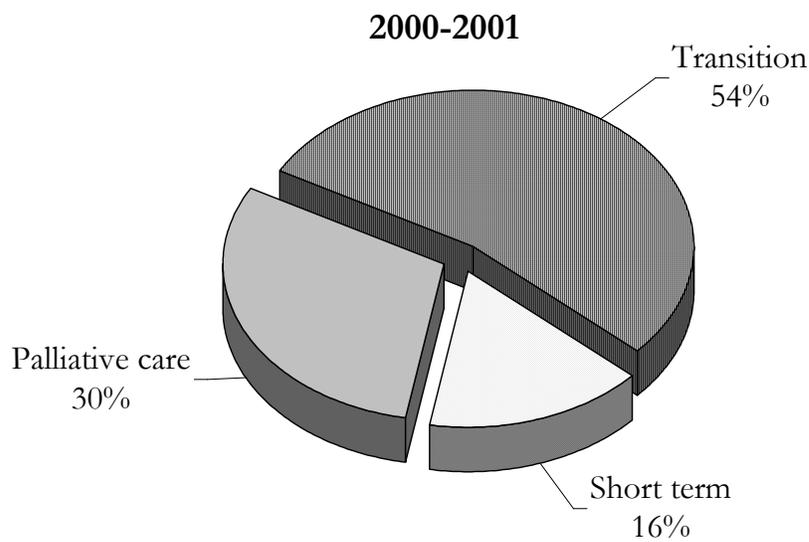
We have observed a significant increase this year in occurrences of dementia (cognitive trouble, drug addiction and behavioural disorders).

Furthermore, other noteworthy health disorders were lipodystrophy (5), HIV secondary anaemia (8) and chronic diarrhea (10).

## Profile of the residents

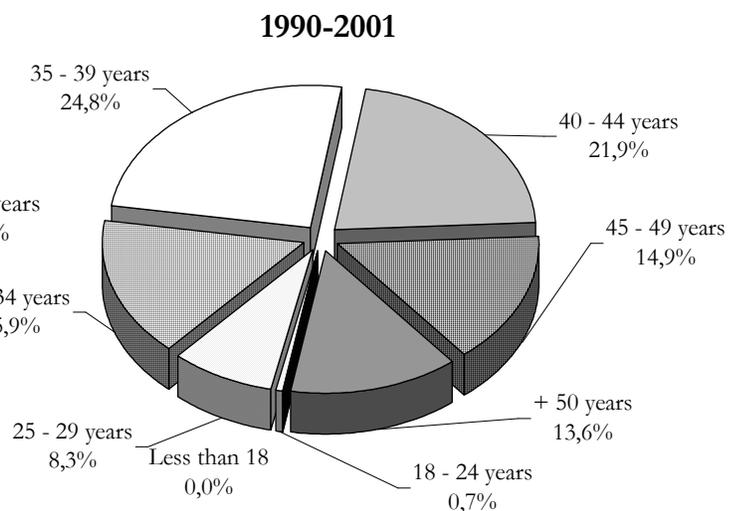
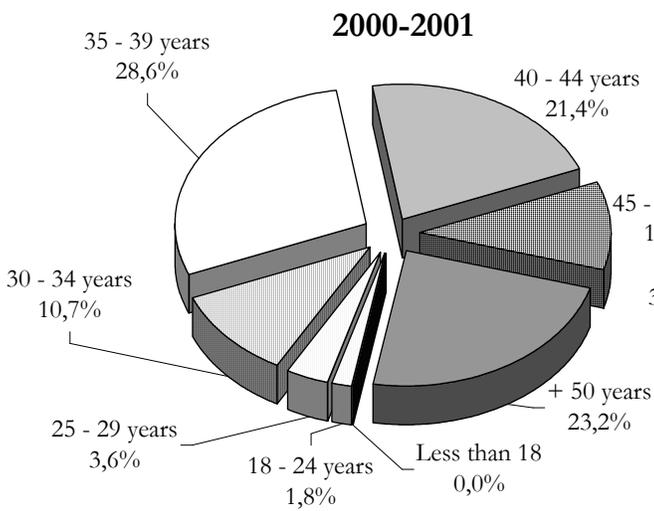
### Number of residents and type of care

|                 | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|-----------------|-----------|-------|-----------|-------|------------|-------|
| Palliative care | 17        | 30,4% | 14        | 40,0% | 156        | 51,7% |
| Transition      | 30        | 53,6% | 14        | 40,0% | 69         | 22,8% |
| Short term      | 9         | 16,1% | 7         | 20,0% | 77         | 25,5% |
| <b>Total</b>    | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |



# Age

|              | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|--------------|-----------|-------|-----------|-------|------------|-------|
| - de 18 ans  | 0         | 0,0%  | 0         | 0,0%  | 0          | 0,0%  |
| 18 - 24 ans  | 1         | 1,8%  | 0         | 0,0%  | 2          | 0,7%  |
| 25 - 29 ans  | 2         | 3,6%  | 2         | 5,7%  | 25         | 8,3%  |
| 30 - 34 ans  | 6         | 10,7% | 2         | 5,7%  | 48         | 15,9% |
| 35 - 39 ans  | 16        | 28,6% | 9         | 25,7% | 75         | 24,8% |
| 40 - 44 ans  | 12        | 21,4% | 14        | 40,0% | 66         | 21,9% |
| 45 - 49 ans  | 6         | 10,7% | 5         | 14,3% | 45         | 14,9% |
| 50 ans et +  | 13        | 23,2% | 3         | 8,6%  | 41         | 13,6% |
| <b>Total</b> | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |

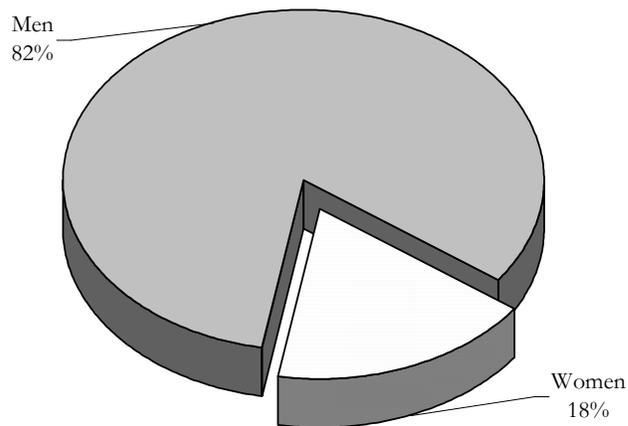


## Gender

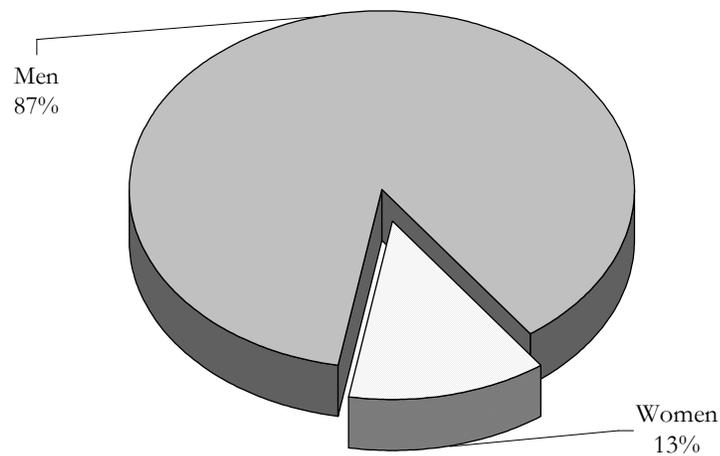
|              | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|--------------|-----------|-------|-----------|-------|------------|-------|
| Men          | 46        | 82,1% | 28        | 80,0% | 263        | 87,1% |
| Women        | 10        | 17,9% | 7         | 20,0% | 39         | 12,9% |
| <b>Total</b> | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |

Note : amongst the men, one person had a feminine identity and was in the process of transgending

**2000-2001**

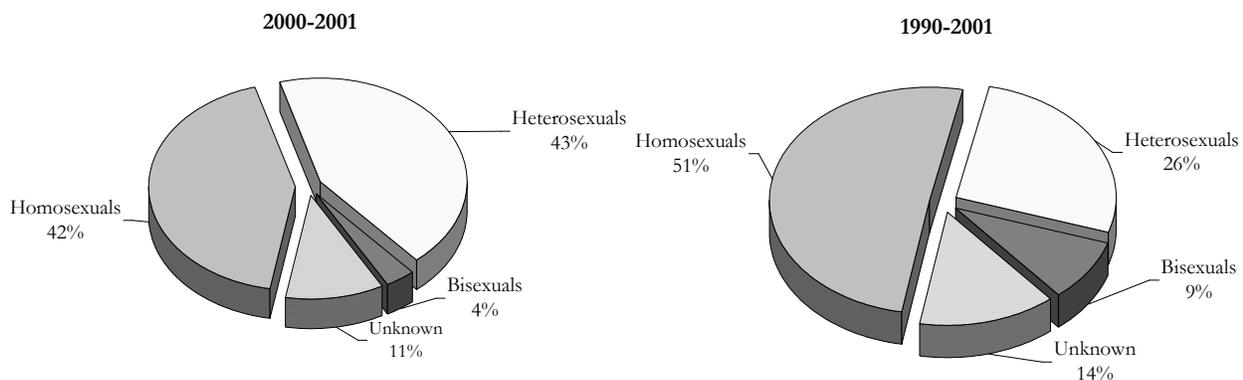


**1990-2001**



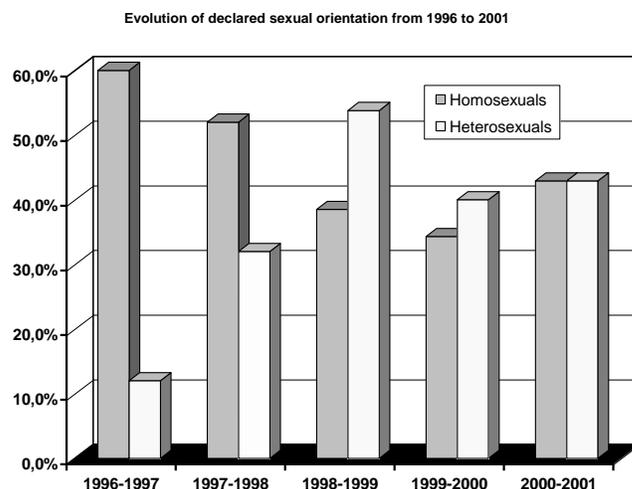
## Declared sexual orientation

|               | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|---------------|-----------|-------|-----------|-------|------------|-------|
| Homosexuals   | 24        | 42,9% | 12        | 34,3% | 153        | 50,7% |
| Heterosexuals | 24        | 42,9% | 14        | 40,0% | 80         | 26,5% |
| Bisexuals     | 2         | 3,6%  | 1         | 2,9%  | 27         | 8,9%  |
| Unknown       | 6         | 10,7% | 8         | 22,9% | 42         | 13,9% |
| <b>Total</b>  | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |



## Evolution of the sexual orientation of residents in the past 5 years

| Year      | Homosexuals | Heterosexuals |
|-----------|-------------|---------------|
| 1996-1997 | 60,0%       | 12,0%         |
| 1997-1998 | 52,0%       | 32,0%         |
| 1998-1999 | 38,5%       | 53,8%         |
| 1999-2000 | 34,3%       | 40,0%         |
| 2000-2001 | 42,9%       | 42,9%         |



## Nationality

|              | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|--------------|-----------|-------|-----------|-------|------------|-------|
| Canadian     | 49        | 87,5% | 30        | 85,7% | 267        | 88,4% |
| Haitian      | 2         | 3,6%  | 2         | 5,7%  | 14         | 4,6%  |
| Others       | 5         | 8,9%  | 3         | 8,6%  | 21         | 7,0%  |
| <b>Total</b> | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |

Others (1990 to 2001) : Chilean (3); French (2); Greek (2); Cuban (2); Nicaraguan (1); Romanian (1); German (1); Portuguese (1); East Indian (1); Colombian (1); Vietnamese (1); Spanish (1); American (1); African (Kenya) (1)

## Mother tongue

|              | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|--------------|-----------|-------|-----------|-------|------------|-------|
| French       | 41        | 73,2% | 26        | 74,3% | 229        | 75,8% |
| English      | 8         | 14,3% | 4         | 11,4% | 40         | 13,2% |
| Creole       | 3         | 5,4%  | 2         | 5,7%  | 15         | 5,0%  |
| Spanish      | 3         | 5,4%  | 2         | 5,7%  | 10         | 3,3%  |
| Other        | 1         | 1,8%  | 1         | 2,9%  | 8          | 2,6%  |
| <b>Total</b> | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |

Others (1990 to 2001) : Greek (2); Romanian (1); German (1); Portuguese (1); Punjabi (1); Vietnamese (1)

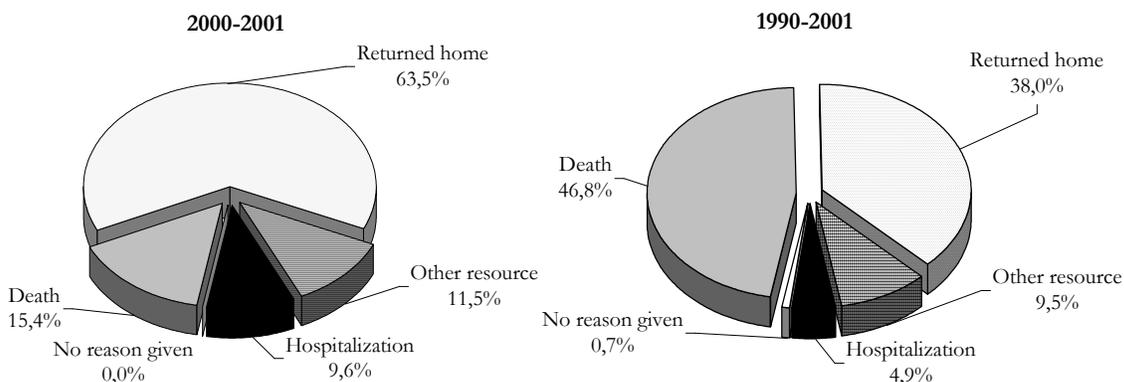
## Financial resources when admitted

|                        | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|------------------------|-----------|-------|-----------|-------|------------|-------|
| Social welfare         | 43        | 76,8% | 24        | 68,6% | 192        | 63,6% |
| Salary insurance       | 6         | 10,7% | 1         | 2,9%  | 44         | 14,6% |
| Quebec Pension Plan    | 2         | 3,6%  | 1         | 2,9%  | 25         | 8,3%  |
| Unemployment insurance | 0         | 0,0%  | 1         | 2,9%  | 9          | 3,0%  |
| Workers' compensation  | 0         | 0,0%  | 0         | 0,0%  | 1          | 0,3%  |
| RRSPs                  | 0         | 0,0%  | 0         | 0,0%  | 1          | 0,3%  |
| No revenue             | 1         | 1,8%  | 2         | 5,7%  | 10         | 3,3%  |
| Unknown                | 4         | 7,1%  | 6         | 17,1% | 20         | 6,6%  |
| <b>Total</b>           | <b>56</b> |       | <b>35</b> |       | <b>302</b> |       |

## Reasons for departure

|                 | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|-----------------|-----------|-------|-----------|-------|------------|-------|
| Death           | 8         | 15,4% | 12        | 37,5% | 133        | 46,8% |
| Returned home   | 33        | 63,5% | 14        | 43,8% | 108        | 38,0% |
| Other resource  | 6         | 11,5% | 4         | 12,5% | 27         | 9,5%  |
| Hospitalization | 5         | 9,6%  | 2         | 6,3%  | 14         | 4,9%  |
| No reason given | 0         | 0,0%  | 0         | 0,0%  | 2          | 0,7%  |
| <b>Total</b>    | <b>52</b> |       | <b>32</b> |       | <b>284</b> |       |

Note : 5 residents died after they were admitted to hospital.



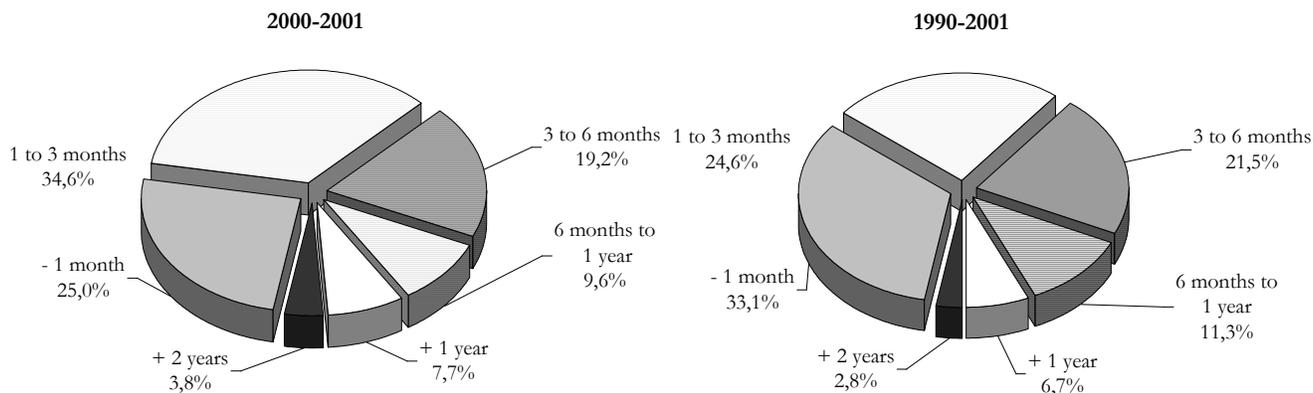
## Number of deaths

|                  | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|------------------|-----------|-------|-----------|-------|------------|-------|
| Maison d'Hérelle | 8         | 61,5% | 9         | 75,0% | 117        | 84,8% |
| Hôpital          | 5         | 38,5% | 3         | 25,0% | 21         | 15,2% |
| <b>Total</b>     | <b>13</b> |       | <b>12</b> |       | <b>138</b> |       |

## Length of stay

|                    | 2000-2001 | %     | 1999-2000 | %     | 1990-2001  | %     |
|--------------------|-----------|-------|-----------|-------|------------|-------|
| - 1 month          | 13        | 25,0% | 8         | 15,4% | 94         | 33,1% |
| 1 to 3 months      | 18        | 34,6% | 12        | 23,1% | 70         | 24,6% |
| 3 to 6 months      | 10        | 19,2% | 7         | 13,5% | 61         | 21,5% |
| 6 months to 1 year | 5         | 9,6%  | 2         | 3,8%  | 32         | 11,3% |
| + 1 year           | 4         | 7,7%  | 2         | 3,8%  | 19         | 6,7%  |
| + 2 years          | 2         | 3,8%  | 1         | 1,9%  | 8          | 2,8%  |
| <b>Total</b>       | <b>52</b> |       | <b>32</b> |       | <b>284</b> |       |

|                            |             |             |             |
|----------------------------|-------------|-------------|-------------|
| <b>Average (in months)</b> | <b>5,07</b> | <b>4,34</b> | <b>4,74</b> |
|----------------------------|-------------|-------------|-------------|



## Average length of stay per program 2000-2001

|                 |                    |
|-----------------|--------------------|
| Palliative care | <b>3,18 months</b> |
| Transition      | <b>8,2 months</b>  |
| Short term      | <b>12,7 days</b>   |

## Associated disorders

|                                      | 2000-2001 |       | 1999-2000 |       | 1998-1999 |       |
|--------------------------------------|-----------|-------|-----------|-------|-----------|-------|
| <b>Total number of residents</b>     | <b>56</b> | %     | <b>48</b> | %     | <b>35</b> | %     |
| Candidosis                           | 24        | 42,9% | 28        | 58,3% | 20        | 57,1% |
| Cryptococcosis                       | 3         | 5,4%  | 2         | 4,2%  | 1         | 2,9%  |
| Cytomegalovirus (C.M.V.)             | 4         | 7,1%  | 8         | 16,7% | 4         | 11,4% |
| Dementia (cognitive)                 | 10        | 17,9% | 2         | 4,2%  | 1         | 2,9%  |
| Depression                           | 7         | 12,5% | 10        | 20,8% | 7         | 20,0% |
| Encephalopathy / leucoencephalopathy | 15        | 26,8% | 20        | 41,7% | 16        | 45,7% |
| Hepatitis                            | 20        | 35,7% | 17        | 35,4% | 8         | 22,9% |
| Herpes                               | 7         | 12,5% | 5         | 10,4% | 4         | 11,4% |
| Recurring bacterial infections       | 2         | 3,6%  | 1         | 2,1%  | 2         | 5,7%  |
| Lymphoma                             | 2         | 3,6%  | 2         | 4,2%  | 0         | 0,0%  |
| Mycobacteriosis (M.A.I. / M.A.C.)    | 0         | 0,0%  | 2         | 4,2%  | 3         | 8,6%  |
| Paralysis                            | 0         | 0,0%  | 3         | 6,3%  | 1         | 2,9%  |
| P. carinii pneumonia                 | 14        | 25,0% | 11        | 22,9% | 12        | 34,3% |
| Bacterial pneumonia                  | 4         | 7,1%  | 2         | 4,2%  | 3         | 8,6%  |
| Kaposi sarcoma                       | 6         | 10,7% | 7         | 14,6% | 5         | 14,3% |
| HIV emaciation syndrome              | 2         | 3,6%  | 3         | 6,3%  | 3         | 8,6%  |
| Drug addiction                       | 32        | 57,1% | 22        | 45,8% | 16        | 45,7% |
| Toxoplasmosis                        | 6         | 10,7% | 4         | 8,3%  | 5         | 14,3% |
| Behavioral troubles                  | 11        | 19,6% | 6         | 12,5% | 4         | 11,4% |
| Mental health troubles               | 9         | 16,1% | 8         | 16,7% | 5         | 14,3% |
| Pulmonary tuberculosis               | 1         | 1,8%  | 0         | 0,0%  | 0         | 0,0%  |
| Zona                                 | 4         | 7,1%  | 3         | 6,3%  | 7         | 20,0% |

### Notes:

Others (2000-2001): Cirrhosis (4); Confusion (1); Uterine cancer (1);

HIV secondary anemia (8); Chronic Diarrhea (10); Diabetes (2); Lipodystrophy (5);

Epilepsy (2); ACV (2).

The associated disorders data reflects the situation over the year.

Data is taken from notes from the physician in our files of all the residents who stayed at Maison d'Hérelle during the course of the year.



### **3. A few facts on housing**

#### **Admission requests**

The admission committee is composed of staff members and one volunteer. Occasionally, a resident will participate in the admission process. An admission request is first submitted and reviewed and this review leads to a meeting with the applicant if the committee concludes that we are able to answer the needs of the applicant.

The admission request can come from the applicant or, as in most cases, from a health professional who assumes the task of initiate the admission process.

When a person is admitted at la Maison, a staff care worker assumes the task of identifying, with the new resident, the objectives of their stay and the help needed to achieve them.

The tasks of the admission committee were considerable this year: responding to numerous admission requests from people who were without shelter, disorganized, drug addicted, homeless, from correctional facilities, from psychiatric care and some awaiting a decision in regards to their status as refugees, and all of them HIV positive! However, the SAGs (Shared Appreciation Groups, an evaluation tool developed by la COQ-sida) allowed us to gain a better understanding of our abilities to respond to which need.

In fact, we find more and more HIV positive people suffering from a variety of different disorders. We did our best to assist applicants who's request was turned

down in finding more appropriate resources. This adjustment lead to concentrate our efforts on persons experiencing psychical or psychological loss of autonomy, requiring transitional care or accompaniment at the end of their life.

The disorders associated with the improvement the health of people living with HIV-aids are numerous and varied: repeated hospitalizations, intake of medication in tremendous quantities, side effects and the appearance of new symptoms such as lipodystrophy, anaemia and chronic diarrhoea. People welcomed at la Maison d'Hérelle were therefore received mainly because of their aids-related needs.

However, it is important to mention once again, that theses men and women are also afflicted with some multiple disorders which make the improvement of their physical and psychological health that much harder.

### Admission requests

|                              | 2000-2001 |       | 1999-2000 |       |
|------------------------------|-----------|-------|-----------|-------|
| Admissions                   | 44        | 66,7% | 27        | 50,9% |
| Admissions in waiting        | 1         | 1,5%  | 3         | 5,7%  |
| Died before admission        | 2         | 3,0%  | 0         | 0,0%  |
| Admissions - other resources | 10        | 15,2% | 20        | 37,7% |
| Withdrawn application        | 0         | 0,0%  | 0         | 0,0%  |
| Applications refused         | 9         | 13,6% | 3         | 5,7%  |
| <b>Total</b>                 | <b>66</b> |       | <b>53</b> |       |

Approximately 35 additional requests were addressed informally to la Maison d'Hérelle : these applicants were scanning the available housing resources (information on the services and admission criteria, etc)

## Returning to the community

Returning to life is often synonymous with poverty, lack of housing and precarious health

### *Poverty*

The vast majority of persons admitted (76,8%) are social welfare recipients. Most declare being without work because of their physical or psychological health.

### *Lack of housing*

Most residents have a desire to return home but the conditions associated with this process increase the difficulty of the challenge, considering their fragile and precarious state of health. The reality with which they must contend is the lack of clean housing at affordable rates.

### *Associated problems and disorders: mental health, drug addiction, prostitution and immigration status*

The last few years have revealed the increasing importance of collaborating with all the partners of the health and community networks, to deal with the multiple disorders that afflict our clientele.

### *Post-care follow-up*

In light of the needs of our residents, we have developed a post-care support program the goal of which is to ensure an adequate preparation to returning home during the resident's stay, as well as continued support in the community, after their departure.

A team of care workers and volunteers will work with existing organizations to ensure support at home. Through this experience, we hope to show that the continuity of

the support will enable our residents to avoid readmission to hospital or community housing. We are also sustaining our efforts towards those responsible for social housing.

## 4. Activities

### Support for loved ones

| Service                                    | Persons | Hours |
|--|---------|-------|
| Psychological support                      | 63      | 743   |
| Information on the progress of the illness | 47      | 190   |
| Advice on care                             | 26      | 144   |
| Legal support                              | 12      | 20    |
| Alternative approaches to health care      | 27      | 94    |
| Meeting with physician                     | 15      | 17    |
| Social economic assistance                 | 17      | 66    |

La Maison has encouraged, from the start, the presence and participation of family members and loved ones. They can equally benefit from information on HIV-aids, preventative measures, hygiene and health care. We often find ourselves dispensing psychological support, legal assistance and support in mourning.

Since the number of persons admitted increased this year, we have come in contact with a larger of loved ones accompanying the residents. The complexity of the illness and the desire of residents to return to the community, force all those around them to mobilize. Friends, family and others are thus enlisted in the plan to return to life.

#### Other services:

As in the past, we have continued to respond, within our means, to the particular needs of the loved ones and family members of the residents, whether through the organization of a family meeting to dispense information on the progress of a resident, by offering psychological support, by attending a memorial service or by helping in the

organization surrounding a return home. An example : at the request of loved ones, a preparation was made for a native ritual, following one death. Another example is the regular contribution to the logistics of a move, assisting a resident to return home.

We cannot forget the conversations around a meal or a coffee, in the dining room, in the living room, in a hallway or on the terrace. These are all part of the informal support which makes the difference.

## **Volunteering**

In this International Year of Volunteering and after celebrating our 10<sup>th</sup> anniversary, volunteering at la Maison d'Hérelle continues to shine. 438 persons gave their time to la Maison d'Hérelle and allowed us to benefit from their expertise. Our senior volunteers remain faithful: for 9 of them, next year will mark their 10<sup>th</sup> year with us.

Despite the fact that it is more and more difficult to recruit new volunteers and keep their interest, some new people continue to join the team and many of them seem intent on staying with us for a long time. However, the new recruits integrate the team for a shorter period of time than in the past, at the time when la Maison d'Hérelle offered mainly palliative care. On a sadder note, we can only deplore the closure of Alternat, whose members contributed greatly to the volunteering of the resource.

Volunteers of la Maison d'Hérelle come guided by their hearts. This is the reason they make it a priority not to judge the residents, even in the face of multiple faceted disorders such as drug addiction, mental health problems, homelessness and others. They accept the residents for who they are, with all the compassion they can dispense. Our volunteers find here a place of love and peace, where they can work in

accordance with their own values, without fear of judgment from the rest of society. What they perhaps don't realize is that it is in great part because of them that la Maison emanates values of humanity and dignity back into society. We take therefore this opportunity to thank them from the bottom of our hearts for their generosity and perseverance.

Among our traditional sectors of volunteering (care, kitchen, alternative approaches to health care, administration, fundraising, etc) a new sector is emerging. The need for external and preventative support, which could often prevent community housing admittance and hospitalization of persons living with HIV-aids, is becoming more and more pressing. A program to answer this need has already been submitted to several partners. Centraide has just granted us a supplementary subsidy of 40 000 \$ to finance this project and becomes our first official partner.

Thus, a team of volunteers is currently in training to assist the psychosocial care-workers in the preparation for departure and post-departure, external support of former residents of la Maison d'Hérelle. Among the tasks which will be considered, there will be cooking, house care, re-enforcement and improvement of the primary social network (support from family and loved ones) and secondary social networks (regular contacts with community support groups) as well as individualized follow-ups.

Volunteers of la Maison d'Hérelle will therefore continue to play a pivotal role with our residents and will have the opportunity to better utilize the skills they acquired over the years. We expect, after a short period of implementation, to widen the scope of this project by offering this training to other aids community residences and enlisting the participations of their volunteers.

Elsewhere, in order to face the challenge of the financial difficulties la Maison d'Hérelle is currently experiencing, we will have to increase the input of volunteers and swell the ranks of the fundraising committee.

Finally, we will have to continue to offer advanced training programs to our volunteers who work with the residents. To fully assume its leadership role, la Maison d'Hérelle will do its utmost to make these programs available to other aids community resources in Quebec. We know that the needs of the clientele are constantly evolving and that it is difficult for the institutional resources to keep up. La Maison d'Hérelle will once again have to show the way.

These are therefore some beautiful projects and wonderful challenges awaiting us once again this year.

***Richard Desjardins***

## **La Maison d'Hérelle or The Spirit of Giving<sup>2</sup>**

(some thoughts from Roger Gagné, volunteers at la Maison d'Hérelle)

After eleven years of existence in the HIV-aids community and more specifically, on the occasion of the International Year of Volunteers, it is right to stop and examine the efforts that go into GIVING at la Maison d'Hérelle.

La Maison d'Hérelle is a family and by its nature, the family is a natural place for the development of the spirit of GIVING.

Who are those precious volunteers? A small group of men and women who, because of the solidarity they feel for a community project such as a home like ours, become guardians of some societal values: love, respect, dignity, compassion, in a word all that that lies at the heart of the relationship between people and is nurtured by GIVING.

These values are truly embodied by our volunteers in the quality of their presence. This way we have seen, in the past eleven years, a mother, a sister or a brother, a lover, some friends, all of whom, despite their daily occupations, find it worthy to accompany a loved one going through a difficult period.

But the members of the staff as well who, well beyond the scope of their work, devote themselves to the well-being of residents : help in all shapes and forms, assistance in reintegrating the community, help to find a home, help to move, support in the integration of a new environment, and many other small services.

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<sup>2</sup>Translation of *L'esprit du Don*, Jacques Godbout, in collaboration with Alain Caillé. Éditions Boréal, 1992, 345 pages.

In short, the vast social field which community work fills today and everyday, is assumed by volunteers and underpaid workers, doing the work of the State : aiding the excluded, the homeless, the drug addicts, etc.

It's the small communities like la Maison d'Hérelle which are witnesses to solidarity. In an interview on Monday October 26<sup>th</sup> 1992, in *Le Devoir* (*Derrière le système marchand, l'esprit du Don*), Jacques Godbout declared the following about community organizations and support groups <sup>3</sup>:

“ I discovered a universe which impressed me very much... Community groups succeed where CLSCs and public organizations generally fail.”

“Contrary to the other system (the public organizations) which operate on a semi-commercial, utilityism basis, this one (community organizations and support groups) rests on the idea of Giving. And myself, seeing only the structures, discovered the universe of mind-sets, of values.”

## ***Roger Gagné***

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<sup>3</sup> Turenne Martine, special collaborator : *L'entrevue du lundi*, *Le Devoir* October 26 1992, p. 12, Jacques Godbout "*Derrière le système marchand, l'Esprit du Don*".

## Volunteering statistics

| Sector                   | Persons    | %     | Hours         | %     |
|--------------------------|------------|-------|---------------|-------|
| Administration           | 16         | 3,7%  | 860           | 4,6%  |
| Alternative approaches   | 6          | 1,4%  | 707           | 3,8%  |
| Other                    | 247        | 56,4% | 3 311         | 17,7% |
| Board of Directors       | 9          | 2,1%  | 971           | 5,2%  |
| Consultants              | 5          | 1,1%  | 138           | 0,7%  |
| Kitchen                  | 12         | 2,7%  | 1 096         | 5,9%  |
| Intervention             | 17         | 3,9%  | 2 132         | 11,4% |
| Staff                    | 44         | 10,0% | 6 033         | 32,2% |
| Employment program       | 0          | 0,0%  | 0             | 0,0%  |
| Residents and loved ones | 52         | 11,9% | 548           | 2,9%  |
| Student trainees         | 30         | 6,8%  | 2 917         | 15,6% |
| <b>Total</b>             | <b>438</b> |       | <b>18 713</b> |       |

### *Thank you!*

*The residents and the team of la Maison d'Hérelle thank you.*

*In this International Year of Volunteers, with seize the opportunity to highlight, once again, the quality of your presence, an essential item in the pursuit and realization of the beautiful project that is la Maison d'Hérelle.*

*Your discreet attentions, the concern you show when one of us is not well, your attentiveness during the more difficult days, give you the likeness of the sentry asking : “ What of the night’s progress?” « Where are the symptoms of dawn?”. Your patience with our hesitations, our many uncertainties, our doubts, is teaching the essential courage of new beginnings.*

*Now more than ever, la Maison d'Hérelle needs its volunteers to maintain the quality of its services and why not, to improve upon them.*

*Thank you, to each and every one of you, for making us appreciate our time of “blossoming”; this LIFE so fragile, filled with surprises, but how precious to enable us to realize our dreams and utopias.*

## **Sectors of involvement of the volunteers**

- ✿ Administration : Board of Directors; co-ordination; recruiting.
- ✿ Assisting the workers: general support; hygiene care; etc.
- ✿ Vigil and attendance
- ✿ Alternative approaches to health management: massotherapy; reiki; therapeutic touch; phytotherapy; aromatherapy; meditation; naturotherapy; homeopathy; etc.
- ✿ Socio-cultural activities: planning and organizing, ticket sales, music, etc.
- ✿ Kitchen assistance
- ✿ Nutrition and healthy eating
- ✿ Fund raising
- ✿ Reception
- ✿ Accounting
- ✿ Psychology
- ✿ Nursing
- ✿ Medicine
- ✿ Painting, woodwork, renovation and repair work
- ✿ The Journal
- ✿ Hair dressing and grooming
- ✿ Sewing
- ✿ Attendance on committees and meetings
- ✿ Accompaniment in-house
- ✿ Accompaniment in the community (medical appointments)
- ✿ Accompaniment for follow-ups (post-departure)
- ✿ Accompaniment of close ones
- ✿ Trainees
- ✿ Transmission and representation: training in other resources, representation before federal and provincial authorities, health care networks, community networks and partnerships
- ✿ Mentoring
- ✿ Training

## **Complementary or alternative approaches to health management**

Since the beginning of the 1990s, la Maison d'Hérelle has offered its residents the opportunity to access all the potentially beneficial therapies available. This included complementary therapies. With these opportunities before them, they were able to make choices, with the assistance of professionals, members of the committee on alternative approaches to health.

The so-called “alternative” therapies place the emphasis on personalized treatment, adopting a holistic view of the individual, or in other words, taking into account the physical, mental, spiritual, emotional and sexual aspects of life. La Maison d'Hérelle's policy is to make use of these therapies as an addition to conventional medicine, in order to increase the comfort of its residents, and not in the hope of replacing medical treatment.

This year again, in our continuous drive to provide overall well-being of our residents, we explored deeply the effects of massage. As in the past, massages were offered by qualified volunteers and staff members

We have also welcomed several massage therapy trainees from well known institutions such as Guijek and Kiné Concept. The residents who favour this approach had the opportunity to receive its benefits more often and it was well appreciated. The presence of several trainees required more attention on the part of the workers who had to welcome and supervise them. However, we can plainly see the benefits of massages for our residents and we believe it essential to continue the trainee program. Some of the supervising procedures are currently being revised.

During the course of the year, several organizations requested our collaboration, recognizing the expertise of la Maison d'Hérelle in alternative therapies. La Maison d'Hérelle has become the francophone authority in the field of complementary approaches for the Community AIDS Treatment Information Exchange (CATIE).

At the request of the Canadian Association of Palliative Care and the Canadian Association of Community Care and Services, the committee members drafted an annex on complementary therapies aiming to increase the comfort level of persons living with HIV-aids, for the francophone version of a document entitled « Family Auxiliaries Training Guide in Palliative Care ».

Carole Durand, a member of the Maison d'Hérelle committee on alterative approaches to health care, collaborated a piece for the magazine « *Info Santé* », distributed by *Robert & Fils*, discussing the treatment of various health issues (epilepsy, hepatitis, etc.) through aromatherapy. She also offered a training session, entitled “Managing Side Effects”, to two aids organizations, C.A.P.- Sida Montérégie and B.R.A.S.-Outaouais. She was also involved with the strategic planning committee on complementary therapies of the Canadian AIDS Society.

Throughout the year, we developed a project entitled : “The self-care through various cultural traditions experimental project”. This exciting project was realized thanks to the collaboration of the Canadian Nurses Association in the scope of “Taking your health in hand, a shared initiative”. The organizing committee is composed if 2 residents, 1 volunteer, 2 staff members and Dr Peter Blusanovics, MD.

Six workshops took place, with the participation of speakers from various cultures (East Indian ayurvedic, African, North American Native Indian, etc.). We noted the

participation of many residents as well as care-workers from other resources (community resources, nurses and a French physician, etc). Evaluation of these workshops revealed a high degree of satisfactions from the participants. They have requested that we continue the thematic evenings and we have committed ourselves to do so.

We wish to let it be known that we are continuing to offer to the residents who desire it, the opportunity to benefit from phytotherapy, aromatherapy, homeopathy, nutrition therapy (medical use of food) and energy therapy. We have included nutritional supplements to these therapies. We are pleased with the results so far.

## Training

La Maison d'Hérelle is very sought after as a training ground for students of various disciplines. Numerous trainee requests come to us, mostly from Europe and in particular, from France.

However, because of the changes implemented in the government employment programs, very few candidates were accepted and we were forced to pull out of the program.

### Student trainees

| Sector                      | Persons   | Hours        |
|-----------------------------|-----------|--------------|
| Special education           | 5         | 799          |
| Massotherapy                | 10        | 159          |
| Social work                 | 2         | 795          |
| Technical nursing           | 2         | 240          |
| Nursing                     | 8         | 1 018        |
| Physician - palliative care | 1         | 112          |
| <b>Total</b>                | <b>28</b> | <b>3 123</b> |

## Promotional activities and outside collaborations

### *Tenth anniversary « Skin stories, Love stories »*

La Maison d'Hérelle was founded in 1988 and welcomed its first residents in May 1990. To celebrate this ten-year milestone, we organized a fundraising activity for which one of the main objectives was to make ourselves known to a wider public and sensitize people to the new realities of aids in the year 2000. In order to achieve this objective, we planned several various events and contacted the media in order to publicize them. The marketing group *Les Majuscules* were mandated to make the main project happen, with the collaboration of the Board of Directors:

- ❑ Soliciting sponsors;
- ❑ Fundraising in hair salons;
- ❑ The main show to close the fundraiser;
- ❑ Ticket sales;
- ❑ Public and media relations;
- ❑ Open house

Many people of various fields accepted to support the project, for which the promotion and presentation were entrusted to **France Castel, the group Le Blues du toaster and Alvaro**. On the day of the event, more than fifty people, stylists, hairdresser, make-up artists as well as television and film personalities, contributed to make it a tremendous success and an unforgivable evening.

Sponsorship for this event brought us some renewed support. We need to mention our new partners who joined the events and to extend our gratitude:

Glaxo Wellcome

Agropur

Émergence 2000

The SAQ

Éclipse Communication Intégrale

TVA

And several others.

The CIBC bank

Eicon Technology

Canada 3000

Femmes Plus Magazine

MAC Cosmetics

CKAC with Isabelle Maréchal

All in all, despite the fact the financial results did not match our hopes, we were able to compensate with increased visibility, renewed support and a number of new partners. Since the majority of the events on the program occurred during the course of the month of December, we were able to be very active and present for the events surrounding the International AIDS Day on December 1<sup>st</sup>.

**We wish to hail the precious support we received or renewed with the following organizations :**

- ☞ CLSC St-Louis-du-Parc, for the weekly visits from Dr. Peter Blusanovics;
- ☞ CLSC *du Plateau*, for their workers : nurses, social workers, physiotherapists and ergotherapists;
- ☞ *L'Université de Montréal*, department of Social Work, for the support of professor Gilbert Renaud;
- ☞ *la Maison Plein Cœur*, for the accompaniment, the support and the van;
- ☞ *la Fondation d'Aide-directe-sida-Montréal*, for the help with the return home of our residents;
- ☞ *la COCQ-sida*, for their support and public representation, and for their reflection work;
- ☞ the aids housing community resources of Quebec;
- ☞ *la Maison Magnus Poirier* ;
- ☞ the *La Clef des Champs* boutique for their support of alternative approaches;
- ☞ the St-Louis-de-France Parish;
- ☞ Isabelle Véronneau, graphic artist;
- ☞ the Dorothée Minville pharmacy;
- ☞ *la Communauté religieuse des Sœurs des Saints Cœurs de Jésus et de Marie*, for the attendance of Lise Germain.



## 5. Financial resources

The principal financial resources of la Maison d'Hérelle are provided through subsidies from the Quebec Department of Health and Social Services (support to community organizations) and from Centraide. We rely as well on the contribution of residents for the housing costs, and on our generous donors.

We wish to thank in particular the principle donors who made it possible for us to continue our mission this year:

|   |           |
|---|-----------|
| Agropur.....                                | 2 500 \$  |
| Les Tournesols distribution centre .....    | 1 000 \$  |
| Eicon Technology Corp.....                  | 2 000 \$  |
| Émergence 2000 Inc.....                     | 1 500 \$  |
| BBCM foundation .....                       | 5 000 \$  |
| The CIBC foundation for good works .....    | 1 000 \$  |
| The Jean-Louis Lévesque foundation .....    | 10 000 \$ |
| Glaxo Wellcome Biochem Pharma .....         | 3 500 \$  |
| The <i>À Contre-courant</i> swim club ..... | 4 561 \$  |

As well as :

|                                 |          |
|---------------------------------|----------|
| The Clément Julien estate ..... | 1 000 \$ |
| William Nash .....              | 1 000 \$ |
| Paul Campeau.....               | 1 000 \$ |
| Dr Richard Morisset.....        | 1 000 \$ |
| Voyages J. Bonin.....           | 600 \$   |
| Netflux Automatisation Inc..... | 600 \$   |
| Roger Rondeau.....              | 500 \$   |
| Duro Dyne Canada Inc.....       | 500 \$   |
| Wright Display .....            | 500 \$   |
| C.A.B.-DÉCO .....               | 500 \$   |
| Sylvain Vinet.....              | 500 \$   |
| Paris Genève Inc.....           | 500 \$   |



## **6. Perspectives for the future**

During the course of the year 2001-2001, we will strive to reach the following goals:

- ❑ Consolidate the financial situation of la Maison, the staff and the daily activity programs, after a year of deficits;
- ❑ Develop and evaluate further the “post-care” program, which has been found to be essential and is supported by the Farha Foundation and Centraide of Greater Montreal;
- ❑ Ensure the survival of the experimental project on self-care, financed by the Canadian Nurses Association in the scope of the program “Taking your health in hand, a shared initiative”;
- ❑ Continue our search for new partnerships and develop stronger ties with groups involved in social housing;
- ❑ Demand an increase in resources attributed to the return to life;
- ❑ Continue our pilot project responsibilities through training and support to other training resources, through conferences, the transmission of information and research results as well as political lobbying.



## **Annex**