

# Who Cares?



## The Economics of Caregiving

### A White Paper

...highlighting the major messages  
from the Caregiving Symposium held on October 30, 2015  
in Blue Bell, Pennsylvania

Felicity Skidmore, Consultant and Editor

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The first of its kind in Pennsylvania, the Caregiving Symposium brought together 150 legislators, caregivers, employers, and the philanthropic community—as well as representatives of governmental and non-profit agencies, community groups and the media.

### Goal

To promote awareness, validate and catalyze a dialogue for action to address the un- and under-reported financial burdens of family caregiving. Nearly 44 million Americans are family caregivers—providing unpaid assistance with the physical and emotional needs of another person. Family caregiving crosses all social and economic boundaries and includes elder care, spousal care, care for children with special needs, and care for wounded military veterans.

### Hosts

Bucks County Women's Advocacy Coalition; A Woman's Place; The Women's Center of Montgomery County; Bucks County Area Agency on Aging; Montgomery County Aging and Adult Services; Bucks-Mont Collaborative



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### Symposium Speakers

#### Keynote Address

Gail Gibson Hunt, *President and CEO, National Alliance for Caregiving*

#### Caregivers' Panel

**Moderator:**

Jen Burnett, *Deputy Secretary, Office of Long-Term Living, Pennsylvania Department of Human Services*

**Panelists:**

Wendy Campbell, *President and CEO, Alzheimer's Association, Delaware Valley Chapter*; Dianne Breen (by written statement), Karen Reed, and Marielena Zuniga, *Family Caregivers*

#### Employers' Panel

**Moderator:**

Dan Bates, *President, Lower Bucks County Chamber of Commerce*

**Panelists:**

William S. Blacker, *Owner, Home Instead Senior Care*; Kathleen Chalmers, *Human Resources Specialist, Moldamatic, LLC.*; Jane Meier Hamilton, *CEO and Founder, Partners on the Path*; Elizabeth M. Walsh, *Executive Director, Bucks County Workforce Development Board, Inc.*

#### Legislative Panel

**Moderator:**

Brian M. Duke, *Former Pennsylvania Secretary of Aging*

**Panelists:**

U.S. Senator Robert P. Casey, Jr. (by video); PA Representative Madeleine Dean; PA Representative Kate Harper

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“ There are four kinds of people in this world: Those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need care.”

– *Rosalynn Carter*

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# 1 Family Caregiving Is a Growing National Crisis

As the American population ages, more of us will need care and fewer will be available to provide care.

*By 2050, more than 20% of the U.S. population will be over 65 years old.*

- Family caregivers provide *unpaid service* estimated at \$470 billion a year—roughly the same as total government spending on the Medicaid program (\$475 billion in FY 2014), the major public program funding nursing home care in this country. The aging of the U.S. population will rapidly increase the scale of this unpaid service.
- As of now (2015), there are seven Americans for every person who needs care. By 2050, only three Americans will be available for every person who needs care. This 2050 caregiving ratio (3:1) has become known as the “caregiving cliff.”
- More Americans are working and more are working at older ages. There are now five generations in the workforce simultaneously.

“ I work three jobs to keep going. My ‘good’ job has fringe benefits and vacation time, which I must use for caregiving crises. I work two additional jobs to pay for the substitute care I need to avoid losing my ‘good’ job.”

Gone are the days when the stay-at-home wife was the typical provider of care. The “new normal” is working *and* being a family caregiver.

- 75% of women 45-60 years old work outside the home.
- 60% of all family caregivers have jobs, more than half of whom are employed full time.
- Almost half of all employed caregivers provide more than 20 hours of family caregiving a week.
- At least 35% of caregivers are men; some estimates put the proportion of employed caregivers who are men as high as 50%.

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## 2 Family Caregivers Are Already Stretched to the Limit

The elderly population in need of care is becoming older and more frail. At the same time, over 10 million family caregivers are helping someone between ages 18 and 49 (including numerous veterans with disabilities).

*“I was a family caregiver for my Mom and Pop for more than 15 years. ... We were in and out of a dozen hospitals and rehabilitation centers. Each time at discharge, I was handed a dizzying array of responsibilities. ... But I wasn't a trained medical professional. And the consequences of making a mistake in the care weighed heavily on me.”*

- People who are 60-70 years old now are caring for parents who are 80-90 or older.
- Later child-bearing puts more people in the “sandwich” generation—having to provide family care for their parents while still raising their own children. At the same time, family caregivers also include minor children caring for adult family members who need help.
  - Medical advances and shorter hospital stays have made family caregivers responsible for tasks that previous generations could not have imagined (e.g., open wound care after surgery, tube feeding, operating medical equipment)—often without receiving any training to do so.
  - Almost half of family caregivers perform medical or nursing tasks for their loved ones with multiple chronic physical and cognitive conditions. Of these, three out of four manage medications, including administering intravenous fluids and injections.

*Annette is providing care for both her parents. [She] has taken a lot of time off as a result of their health problems. ... One doctor appointment turned into an all-day affair that cost her a full day of work. In addition, her father was hospitalized in a psychiatric hospital for an acute episode. She ... had to cancel several days of work, her own health appointments and her volunteer work.*

Family caregivers universally say they have too little time.

- Unlike most child care responsibilities, family caregiving obligations often come without warning, persist for uncertain periods that can stretch over many years, and get more complex over time.
- A previously healthy and active family member may need care without warning. And ongoing caregiving is beset by sudden crises.

*Out-of-pocket caregiving costs do not vary with ability to pay. Caregivers with family incomes below \$25,000 a year (roughly the official poverty line for a family of four) spend almost as much out of pocket as caregivers with family incomes twice as high (\$50,000 a year, which is the U.S. median family income). At this level of financial burden for low-income families, the danger of bankruptcy through caregiving becomes very real.*

Caregiving leaves many family caregivers financially strapped.

- Family caregivers spend, *out of their own pockets*, over \$5,000 a year on behalf of those in their care—an amount that almost doubles for family members who must care from a distance. This financial drain is not a matter of choice. It is for *necessities* (e.g., transportation to routine medical visits, prescription copays, even food). Some family caregivers also pay for care when they themselves are unavailable. And symposium participants emphasized that adequately trained people for caregiving jobs can be hard to find.

*Income-related losses for family caregivers age 50 and older who must leave the workforce to provide care average more than \$300,000 over a caregiver's lifetime.*

- Family caregivers lose job security, employment benefits, employer-based health insurance, savings for retirement, and social security contributions. This combination of retirement penalties causes more financial hardship for women than for men, because women still earn less per hour than men for equivalent work, reducing their pension savings in the first place.
- Until the mid-1990s, increasing proportions of family caregiving were augmented by some paid help. This trend has reversed, however, with increasing proportions of family caregivers carrying the load alone. Two-thirds of older people with disabilities who receive care at home now get *all their care* from family caregivers.

*Urgent research question:  
How important is lack of  
money in causing caregiver  
stress? Would it be more cost-  
effective to combat stress by  
giving poorer caregivers  
money—rather than offering  
them programs that treat  
stress directly?*

## Family caregiving is strongly associated with deteriorating caregiver health.

- Family caregivers are less healthy than the general U.S. population. Between 17% and 30% of family caregivers perceive their health as fair to poor.
- Between a quarter and a half of all caregivers assisting older persons meet the diagnostic criteria for major depression. Higher proportions have clinically significant symptoms of depression.
- Employers pay 8% more for the health care of employees with eldercare responsibilities, costing U.S. businesses an estimated additional \$13.4 billion a year.
- Caregivers often neglect their own care needs because of the time and energy demands of family caregiving. Family caregivers providing care to people with Alzheimer's Disease have higher mortality rates than other family caregivers.

**“** *More doctors. More appointments. I am always on the phone ... with someone about Dad. I am thrust into ... navigating the maze of the medical system. I have lost my life. Is this healthy? I know it's not. ...”*

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## 3 The Business Case Is Strong for Employers to Support Workers Who Have Caregiving Responsibilities

Businesses cannot be expected to hurt their bottom line. But statistics suggest that supporting family caregivers can provide substantial savings to the business community.

*The average recruitment and retraining cost incurred to replace a single full-time employee is estimated at \$500.*

*The cost of a single full-time employee changing to part time is estimated at \$300.*

- Full-time employees who are caregivers cost Corporate America over \$33 billion a year, according to the Metlife Study of Employer Costs for Working Caregivers. These costs include absenteeism, unpaid leave, changing from full to part time, workday interruptions, and lost productivity while working. Not included are the costs (noted above) that businesses incur because of the additional health care needs of employed caregivers. Further, the Metlife estimate includes only care for recipients age 50 or older. Estimates that include care for younger care recipients put the cost much higher.
- Most workers who are caregivers are knowledgeable, experienced, valued employees. Their productivity slips because they are faced with caregiving responsibilities beyond their control.

## Relatively inexpensive initiatives can pay for themselves many times over in employee stability and retention.

- Caregivers do not want handouts from their employers. A fundamental need is work flexibility. Many inexpensive types of flexibility can help. Employers can learn from comparable businesses about which best practices are most cost effective for their particular business, which depend on firm size as well as type of business. Examples include:
  - **Flextime.** Rather than enforcing a strict 9 a.m. to 5 p.m., Monday-through-Friday work week, many businesses give employees options. Examples include a 10-hour day, four-day work week; changing the start and matching end times of the work day to accommodate early morning or late afternoon care needs; enabling employees with caregiving responsibilities to reserve a time in the day for phone calls that can't wait.
  - **Telecommuting.** Many jobs do not need physical worker presence at all times. Some businesses have found that

“Half of my staff is dealing with caregiving issues. If we hadn't known that, we couldn't have responded. What we did was to hire an IT consultant to come in and set up remote access to all our files. If something comes up, any of us can now work from home. My vice president can do all the financials from home. My marketing and public relations people can work from home. We were able to make it happen.”

employee productivity improves when workers can do at least part of their jobs from home (meeting their needed caregiving presence while efficiently completing office tasks).

- **Fringe benefit flexibility.** Some employers have found that enabling staff to exchange the way they take fringe benefits helps productivity (e.g., trading off vacation or holiday days, broadening sick leave to cover other family members who need care). Phased-in retirement plans can also help.

*One employer found it efficient to permit workers to help with a co-worker's tasks when caregiving crises strike. That employer then encouraged task-sharing by giving public recognition to all employees who provide task-sharing help.*

Human resource (HR) departments know your employees and can help identify creative ways to support valued employees who have family caregiving needs.

- HR personnel deal with a firm's employees every day. Encourage your HR staff to help identify which types of supports the caregiving employees would appreciate most.
- Consider adding eldercare expertise to the HR department—either new training for existing HR staff or a new hire. Such expertise is likely to be widely appreciated and used by

employees needing information about available services in the community, or about strategies to help cope with new caregiving responsibilities.

- HR staff can also identify employees who have undergone sudden changes in their work behavior—a pattern of lateness that was never previously apparent, or a sudden drop in productivity unlike any in that employee’s history—and provide informed understanding and information on sources of help and advice.
- Increasing numbers of employers offer Employment Assistance Programs (EAPs). EAPs are designed to help employees with personal problems that affect their job performance, health, and well-being. These programs are typically free to the employees and provide short-term counseling to employees and their family members. Evidence suggests EAPs can be cost-effective and are probably best managed by a third-party company (for reasons of confidentiality as well as efficiency).

*Do not assume you know best what your employees need or want. Ask them first. Then phase in incremental changes slowly, to see what works best for your firm—and for the people who work for you and are indispensable to your business success.*





## 4 Helpful Steps Family Caregivers Can Take

Although family caregiving responsibilities can hit suddenly and unexpectedly, potential caregivers can often take steps to prepare for such responsibilities.

- As family caregiving becomes more likely, several preparatory steps can be valuable. These include:
  - Compile regularly updated lists of all the family member's health conditions, health care providers, conditions, surgeries, medications, and test records. Put lists where you can be sure to find them. If crisis strikes take them to the hospital; these lists will be invaluable in speeding up diagnosis, treatment and follow-up.
  - Help the family member think through health and estate planning issues, preferably with legal help. Important potential examples of ways to ensure the family member's wishes will be respected include: (1) drawing up a health care power of attorney and/or a durable power of attorney, (2) making a will for distributing financial and real property after death, and, (3) making a "living will," also called an Advance Directive, including deciding what treatment will/won't be wanted (e.g., feeding tube) or whether a Do Not Resuscitate directive is appropriate. If these steps are not already in place when they become relevant, the hospital or state law will take over such decisions, which can be contrary to the wishes of all involved.
  - Even if the person who needs care is unwilling to consider giving up some independence, there are many supports available to help them remain at home. At least get an assessment to help you plan before the need arises. Your local Area Agency on Aging can provide an assessment for free, or connect you to an entity that can. Private geriatric care managers are also available for a

“ All you caregivers in my experience don't ask for enough help. Ask. Ask. ... We are out there. We will try to help you. See what we can do. Connect with people who can help you.”  
– PA State Representative

fee. When you get an appointment for an assessment, be sure to take it even if the timing is inconvenient. Services such as home care or facility placement may be available on a subsidized or private-pay basis. But there are eligibility requirements and sometimes long waiting lists for subsidized services. You need to know what is out there, and the opportunity for an assessment and care planning by a professional who knows the field can help you plan to get the help you may need now, and strategize for the future.

- Many shoulder the burden of family caregiving responsibilities willingly. BUT that does not lessen the burden. However reluctant you may be to ask for help, the social good requires you to help educate the wider public and to get the help you need.
  - *If you are employed and a family caregiver, go to your HR department.* Get them to understand the types of assistance that would help you the most. Businesses may not broadcast every detail of the accommodations they are prepared to

make. But asking what they are prepared to do is essential in educating them about your needs and the needs of those like you. Note that the Americans with Disabilities Act prohibits employment discrimination against anyone who cares for a person with disabilities covered under the Act.

- *Go to your state representatives and forcefully make your case.* You elect them precisely to serve your best interests. Their local offices will know, or can find out for you, what caregiving services and supports are available, where to go, and how to proceed.
- *Raise the awareness of your local community to family caregiving issues.* Band together with other family caregivers in your area to make your collective voices heard.





# 5 The Public Sector's Important Responsibility Is to Identify and Implement Cost-Effective Policies to Enable American Families to Prepare for, to Continue, and to Thrive in Their Unpaid Family Caregiving Roles

*The strongest single predictor of (expensive) nursing home placement is not the condition of the care recipient, but lack of a family caregiver.*

*This simple fact is proof that actual service needs are not typically the fundamental problem. Too often, the problem is collapse of a family's caregiving support system.*

The fundamental role of American government is to deal cost-effectively with issues that are too broad to be resolved without public action to improve the public good. The looming caregiving crisis is a perfect case for cost-effective government action.

- The vast majority of the long-term caregiving needs of our society are currently being met by family members, who provide the necessary services willingly and for free. But the care needs of our aging society are growing and the population able to meet those needs is shrinking.
- Most people who need long-term care prefer to remain at home. Home is the least expensive place to receive care. Family caregivers are by far the least expensive source of care and they will continue to give it, and at the highest possible quality.
- If our voluntary caregiving system should prove unable to bear the increasing load, however, the public purse will be more than stretched to the limit and the implications for care quality are certain to be disastrous.

Both federal and state legislative action can be important potential sources of public sector help. Some existing laws need reauthorizing or amendment. Other measures have been introduced but need political pressure to move them up the policy priority list. Needed federal and state action includes:

- *Reauthorization of the Older Americans Act (S. 192)*. The OAA is the major vehicle for the organization and delivery of social and nutrition services to Americans age 60 and older and their caregivers. Among its many administrative arms are the 629 local Area Agencies on Aging. Shockingly, authorization of the OAA expired in 2011, and Congress has yet to agree on the terms of its reauthorization.
- *Passage of the Caregiver Corps Act (S. 2842)*. Introduced in the 113th Congress (2013-2014) but not passed, this legislation would require the U.S. Secretary of Health and Human Services to develop a toolkit and guidance for local non-profit organizations to train volunteers to provide respite care (i.e., substitute care to give family caregivers a temporary break from their caregiving demands). It would not supplant direct care workers but supplement their efforts.
- *Passage of the RAISE Family Caregivers Act (HR. 3099)*. Introduced in the 114th Congress (2015-2016) but not yet passed, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act would require development, maintenance, and updating of an integrated national strategy to support family caregivers. An advisory council would bring together federal and local agencies, private sector representatives, caregivers, and persons who need care to make recommendations on specific actions government, communities, health care and other providers, employers, and others can take to recognize and support family caregivers.
- *Redesign and passage of the failed CLASS Program*. The Community Living Assistance Services and Supports (CLASS) program was initially established under the health care reform Patient Protection and Affordable Care Act of 2010. CLASS was a form of insurance to protect against the future risk of needing long-term care. As a voluntary program, it was judged not viable in its current form, because its voluntary nature prevented it from establishing a sustainable funding base. The issue of insuring against the risk of long-term care expenses is still very much with us, however, since private insurance companies are withdrawing from the long-term care insurance market. Many observers see an urgent need for a CLASS-like federal program, amended to establish the mandatory participation necessary for funding stability.

Action is needed on these bills introduced in the 2015-2016 legislative session:

- ✓ *Reauthorization of the Older Americans Act (S. 192)*
- ✓ *Passage of the Caregiver Corps Act (S. 2842)*
- ✓ *Passage of the RAISE Family Caregivers Act (HR. 3099)*
- ✓ *Redesign and passage of the failed CLASS Program*
- ✓ *Passage of PA extensions to the Family and Medical Leave Act (PA SB. 681 and HB. 429)*

- *Passage of Pennsylvania extensions to the federal Family and Medical Leave Act. (SB. 681 and HB. 429).* The Federal Family and Medical Leave Act (which will be 23 years old in February 2016) permits eligible employees to take a certain number of weeks of unpaid leave for bonding with a newborn, recuperating from a health issue, and caring for a family member under certain conditions. All

Pennsylvania employers must comply with the FMLA, but the law does not cover certain other family members. Therefore, SB. 681 and HB. 429 (identical) were introduced in 2015 and referred to the respective Labor and Industry Committees. These bills would extend the coverage of the FMLA to employees who need to care for siblings, grandparents and grandchildren in certain cases.

State legislative initiatives obviously vary according to a state's specific needs. But one model for state action has made progress in several states that addresses the universal need for more integrated post-hospital care and should be pursued in all states.

- *The CARE Act.* Developed by AARP, the Caregiver Advise, Record, Enable (CARE) Act supports family caregivers when loved ones go into the hospital, by establishing an important triad: doctor, patient, and caregiver. The Act would require the name of the family caregiver to be recorded upon hospital admission, family caregiver notification when the loved one is to be discharged, and pre-discharge family caregiver instruction on the medical tasks the family caregiver will perform at home. Symposium participants noted two important caveats about the design

and provision of post-hospital care, however. First, the regular family doctor is often bypassed in post-discharge planning. Second, in too many cases, the post-discharge plan is never carried out because there is no follow-up monitoring.

*In Pennsylvania, lawmakers are considering The CARE Act (HB. 1329), a bill in the 2015-2016 legislative session.*

A comprehensive review of the sprawling set of the public long-term services and supports (LTSS) system is badly overdue. The LTSS policy environment is riddled with inconsistencies and lack of parity or coordination across programs—many of which have come about through regulatory provisions that no longer match America's current age distribution, family composition, or cost of living. Such a review could be included in the mandate of the national commission required by the RAISE Family Caregiver Act (H.R. 3099). A few examples make the point:

- *Program eligibility restrictions that do not always match today's caregiving reality.* The OAA, for example, defines older Americans as age 60 and older. This does not accord with the many grandmothers who are much younger than that, are employed, and are the primary caregivers of their grandchildren who need care.
- *Exclusionary barriers that impede complementary assistance from different programs.* One children's program, for example, provides payment for a low-income family caregiver. But if the time comes to establish guardianship, that primary caregiver will either be excluded from guardianship or forced to lose the

financial assistance that has been enabling the primary caregiver to provide help. Foster care, adoption, and related programs can have similarly inconsistent and arbitrary exclusionary barriers.

- *Provisions that have not kept up with today's cost of living.* One glaring example is the monthly spending allowance the Medicaid program provides to nursing home residents who are Medicaid beneficiaries. The allowed amount is currently \$45 a month, out of which residents are supposed to pay for “extras” such as a haircut, cable TV, even in some cases laundry!
- *A decision date for the start of financial assistance that penalizes community-based care versus (much more expensive) nursing home placement.* Under the Medicaid program, which is the major public funder of nursing home placement, financial need for nursing home care can be established up to 90 days retroactively, to the date of admission—ensuring that facility care can be paid. The same is not true for individuals who qualify for nursing home care but prefer to receive their care at home. Lack of presumptive eligibility pushes some consumers into unwanted facility placements because their caregivers are unable to provide

the needed level of care during the often-lengthy wait for eligibility determination for care at home. Unlike nursing facilities, caregivers cannot be reimbursed for family care provided during this time. Presumptive eligibility needs to be available in Pennsylvania to permit consumers to receive prompt care in the appropriate setting of their choice, as pledged in the Olmstead Act.

In Pennsylvania, Medicaid funding is not available for those who qualify for a lesser level of care, such as Personal Care Homes and Assisted Living Facilities, leaving caregivers at risk of becoming exhausted until their care recipient's health declines to the point of eligibility for nursing home level of care. Insufficient funding for non-Medicaid programs for care at home also contributes to declining health for older and disabled adults and greater burdens for caregivers.

*Presumptive eligibility needs to be available in Pennsylvania to permit consumers to receive prompt care in the appropriate setting of their choice, as pledged in the Olmstead Act.*

Many excellent recommendations, large and small, have been proposed to further improve the integration and adequacy of the nation's family caregiving support system. A few examples again make the point:

- To help ease the retirement penalty of leaving the workforce early: *Provision of Social Security credit, or an income tax credit, for caregivers who must leave the workforce to provide care.*
- To recognize the reality of today's family: *Inclusion of step-parents, step-children, and in-law relatives as eligible family members in, for example, the Family and Medical Leave Act.*
- To avoid the current legal danger of liability for any remaining rental payments when a person can no longer live at home: *State legislation to provide for early lease termination in cases of incapacity or death.*
- At the bureaucratic level, state collective bargaining contracts often restrict the working hours of public employees to Monday through Friday, 8:30 a.m. to 4:30 p.m.—even those tasked specifically with assisting family caregivers to get the help they need. This is precisely when most employed caregivers are least likely to be free to seek help.



## 6 The Community-at-Large Must Join Together to Force and Facilitate Solutions to the Growing Caregiver Crisis

With the demographic ground shifting rapidly under our feet, we must rethink and regroup to enable our society—and that means every one of us—to continue the vital work of supporting family members and friends who either provide caregiving or need emotional or physical support in their daily lives.

“Alzheimer’s Disease is the fifth leading cause of death for people 65 and older. It is grossly misdiagnosed. I suspect it would be the third leading cause of death if we had accurate death certificates.”  
– Symposium Panelist

- *Look around you.* Learn about your neighbors. Identify those who need help and those who may be able to give help. Organize the community to provide respite care and run errands for those who need the help volunteers can offer.
- *Write about what you see.* Send Letters to the Editor, send Op Ed pieces to your local paper. Describe events you have seen that illustrate care gaps, unmet needs. Your observations may be picked up by the media and used to further publicize what you have seen firsthand.
- *Contact your state representatives and forcefully make the case.* These are the people you elected to help you and your community with state and local needs. Your representatives need and invite your pressure. They want help in identifying what their constituents need. And you need their help to champion the causes you value.
- *Contact your federal representatives.* Pressure them on any of the public policy suggestions of the previous section, or any others you learn about and want to champion.

Listen to this symposium panelist,  
who is also a primary family caregiver:

“*I never planned on sharing my story. Nor would I have wanted to. But if I can bring some light on the difficulties ... this effort will be worthwhile. ...*

*I have mixed emotions about raising my grandson alone. It is not the traditional nuclear family I grew up with. I am almost 60. My grandson is 9. He experiences anger, stress, rejection. ... This commitment has brought enormous challenges. ...*

*Please help us to be able to do a better job being caregivers and, as a result, the world will be a better place.”*

## Many Thanks to the Symposium's Generous Sponsors



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For more information,  
and to get involved, please send an email to the  
Bucks County Women's Advocacy Coalition.

[info@bcwac.org](mailto:info@bcwac.org)